Coping in children and adolescents aged 8-16 years old with food allergy, and the development and validation of the Coping Scale for Food Allergy (CS-FA)

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Doctor of Philosophy

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January 2019

Abstract

Children and adolescents with food allergy (FA) face complex and substantial lifestyle changes to successfully manage their condition, and are the age group with the highest proportion of visits to hospital emergency departments and fatal reactions. Research has shown the associations between effective coping and better health outcomes. However, this has not yet been examined in children and adolescents with FA.

This thesis presents four studies exploring how children and adolescents aged 8-16 with FA cope. A mixed-method approach guided the research, and the control-based model of coping (Compas et al., 2001) underpinned the identification and analysis of coping strategies. A systematic review was first conducted, which identified a range of coping strategies employed by children and adolescents with FA. However, only two published studies had coping as the primary aim, and only three studies included children below 11 years old. Semi-structured interviews were then conducted with 8-16 year olds which provided a greater insight into the coping strategies used. Some differences in coping associated with autonomy were identified, and so analysis was conducted on the 8-11 and 12-16 year olds separately. However, the types of coping strategies used between the two age groups, and the reasoning behind their uses, remained largely similar. The final study utilised the findings from the first three studies to inform the development of a Coping Scale for Food Allergy (CS-FA) which shows good preliminary reliability and validity.

Future research should consider investigating the impact of FA education, peer support, and the role of parental influence on the development and use of coping strategies, and if strategies differ between different types of FA. Clinicians could use the CS-FA to open dialogue with their patients to further understand how they are coping with FA, and where challenges may lie.

Keywords: coping strategies, mixed methods, scale development, outcome measures, paediatric

Dedication

To my wonderful mother for her ongoing love and support, you are my biggest inspiration. And to my late father who could not see this PhD journey completed. You are missed every day.

Acknowledgements

I would firstly like to thank Allergy UK and Aston University for kindly funding this PhD. Special thanks go to the children and adolescents who so generously gave up their time to participate in my research. Without you, this would not have been possible, and I will remain forever grateful. I would like to thank my principal supervisor, Dr Rebecca Knibb, and my associate supervisor, Dr Richard Cooke, for their support and encouragement. You both pushed me to the best I could be, thank you for helping me navigate this PhD journey, and for always being so enthusiastic about my work.

A huge thank you to my family, friends and colleagues who have been there for me over the years. There are far too many people to list. Mum, thank you for always supporting whatever decision I make and encouraging me to go for what I want. Thank you for the regular food parcels as well, and making sure I was well fed! Stuart, thank you for always having some words of wisdom when times would get tough. Jim, for always supporting me and the family since before my undergraduate days. Elsa, for keeping me company late into the night when I'd be writing. To Dr Farina Kokab, Dr Mable Nakubulwa and Dr Alan Poots, thank you for all the PhD support and advice you have given me during these last few months. To my wonderful friends, old and new, thank you for always being there for me, for the words of encouragement, the visits, and for being so understanding and patient with me during this journey.

To my PhD partner in crime, Lydia Aston, I could not have done this without you. We have shared many highs and lows, but we have never, ever stopped laughing. Thank you for being you! I have gained a life-long friend, DDC forever. Special thanks also go to Kristina for calming my pre-viva nerves, and to Ian – words cannot express my gratitude for all your help and patience in helping me understand, and on the rare occasion, enjoy stats. Chapter 6 is dedicated to you.

Last, but no means least, to my wonderful boyfriend Jonty. You have been so patient with me, and have endured endless chats about food allergy and health psychology. Thank you for always believing in me and for being my rock, for providing endless cups of coffee and snacks, for proof-reading my work, picking me up when I fell down, and for the reassuring words when I needed them – the list of what you have done for me could go on and on. Now my PhD has come to an end, I am going to be there for you as you complete yours.

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List of abbreviations

AAI	Adrenaline auto-injector
B-IPQ	Brief Illness Perception Questionnaire
CBMC	Control Based Model of Coping (Compas et al., 2001)
CS-FA	Coping Scale for Food Allergy
FA	Food allergy
FAIM	Food Allergy Independent Measure
FAQLQ-CF	Food Allergy Quality of Life Scale - child form
FAQLQ-TF	Food Allergy Quality of Life Scale - teenage form
HCP	Healthcare professionals
ICC	Intra-class correlations
MMAT	Mixed Methods Appraisal Tool
NICE	National Institute for Health and Care Excellence
PCA	Principal components analysis
PREM	Patient-reported experience measure
PROM	Patient-reported outcome measure
PTSS	Posttraumatic stress symptom
QoL	Quality of life
RCADS	Revised Children's Anxiety and Depression Scale
T1D	Type 1 diabetes
TA	Thematic analysis
TMSC	Transactional Model of Stress and Coping

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CHAPTER 1 Introduction

1.1. Overview

In this chapter, I provide an overview of the two fields of enquiry that are the focus of this research: food allergy (FA) and coping. The chapter starts with an overview of the symptomatology, diagnosis and management of FA. This is followed by a brief discussion of the impact that FA can have on children and adolescents, including the impact on their psychosocial functioning and Quality of Life (QoL).

The next section summarises research showing how children and adolescents cope with the stressors associated with long-term conditions and outlines several models of coping used in paediatric research, which are briefly discussed. I provide more specific focus on coping with FA and summarise the limitations and gaps in knowledge identified from current research.

The third section discusses the measurement of coping and patient reported outcome measures (PROMS) and provides examples of existing coping measures that have been used in research with children and adolescents diagnosed with a chronic illness. This section includes a case being made for the development and use of a condition specific scale to address the limitations associated with using a generic coping scale.

At the end of this chapter, the aims and objectives of this thesis are outlined.

1.2. Food allergy

In 2004, the World Allergy Organisation published a "nomenclature" for allergic diseases, including FA (Johansson, Bieber, Dahl, Friedman, Lanier et al., 2004). They defined FA as an adverse immunologic response to food proteins which can be either immunoglobulin E (IgE)-mediated (where the antibody is directed to specific food proteins) or non-IgE mediated (caused by other cells within the immune system) (Waserman & Watson, 2011). All other reactions to food, such as intolerances, are classified as non-allergic food hypersensitivity (Johansson et al., 2004).

The prevalence of FA in the United Kingdom (UK) appears to be increasing and is currently thought to affect up to 10% of the general population, though this is still open to debate (Grimshaw et al., 2016; Gupta et al., 2011; Kotz, Simpson & Sheikh, 2011). According to the Food Standards Agency (2016), it is believed that between 1-2% of adults and 5-8% of children have a clinically diagnosed FA. Rates of FA are highest in infancy, with approximately 5-6% of children aged up to three years diagnosed with the condition. However, many children outgrow their FA, particularly those who have been diagnosed with an egg or milk allergy (Venter et al., 2008).

There are fourteen common food allergens identified within Europe. These are: cereals (containing wheat and gluten), shellfish, eggs, fish, peanuts and tree nuts, cow's milk, celery, mustard, sesame seeds, molluscs, soya, lupin and sulphites (Venter & Meyer, 2010). However, in the UK, FA are mainly caused

by eight main foods: cow's milk, egg, peanuts, tree nuts, sesame, crustaceans, fish and wheat (Venter et al., 2006).

1.2.1. Food Allergy: Symptomatology

The symptoms of an allergic reaction can occur on the skin, within the gastrointestinal system and the respiratory system. Gastrointestinal symptoms can include oral pruritus (itching of the mouth), swelling of the lips or tongue, a sensation of tightness of the throat, nausea, and abdominal cramps. Skin reactions can include pruritus (severe itching), rashes or flushing, urticaria (hives) and angioedema (swelling). Respiratory symptoms can include allergic rhinoconjunctivitis such as conjunctivitis and rhinitis, congestion, sneezing, nasal pruritus (itching of the nose) and asthma. Reactions can also differ according to whether the FA is IgE-mediated or non-IgE-mediated (National Institute for Health and Care Excellence, 2011) A list of the difference in reactions between IgE and non-IgE mediated allergies is provided in Table 1.1.

Table 1.1: Signs and symptoms of possible food allergy in under 19s - adapted from NICE guidelines, 2011

IgE-mediated	Non IgE-mediated
The skin	
Pruritus	Pruritus
Erythema	Erythema
Acute urticarial – localised or generalised	Atopic eczema
Acute angioedema – most commonly of the lips, face and around the eyes	
The gastrointestinal system	
Angioedema of the lips, tongue, palate	Gastro-oesophageal reflux disease
Oral pruritus	Loose or frequent stools
Nausea	Blood and/or mucus in stools
Colicky abdominal pain	Abdominal pain
Vomiting	Infantile colic
Diarrhoea	Food refusal or aversion
	Constipation
	Perianal redness
	Pallor and tiredness
	Faltering growth in conjunction with at least one or more gastrointestinal symptoms above (with or without significant atop eczema)
The respiratory system (usually in combination with one or more of the above symptoms and signs)	
Upper respiratory tract symptoms (nasal itching, sneezing, rhinorrhoea or congestion (with or without conjunctivitis)	
Lower respiratory tract symptoms (cough, chest tightness, wheezing or shortness of breath)	
Other	
Signs of symptoms of anaphylaxis or other systemic allergic reactions.	

In more severe cases, reactions can be classified as anaphylaxis, a severe reaction which can be life threatening or fatal. It is characterised by a rapidly progressive and multiple organ system reaction, targeting the gastrointestinal system, respiratory system and the skin. Eventually, this can lead to cardiovascular collapse (Sampson, 2005; Sicherer and Sampson, 2010). Anaphylaxis can be potentially fatal if there is a delay in administering treatment, such as an adrenaline auto-injector (AAI; Posner & Camargo, 2017). Research by Pumphrey and Gowland (2007) identified a number of factors associated with the majority of fatal FA related anaphylaxis in the UK. Among adolescents and young adults these included cases where (1) an AAI should have been carried but was not, (2) where an AAI was carried but was either not used correctly or not used at all; and (3) with foods that had been catered, such as those prepared at restaurants.

1.2.2. Diagnosis of food allergy

The National Institute for Health and Care Excellence (NICE, 2011) has published specific guidelines for the diagnosis of FA in the UK in children and young people under the age of 19. These guidelines advise a clinical history and examination of the patient, and an allergy-focused clinical history tailored to the presenting symptoms and the age of the child or young person (Muraro et al., 2014). Based on the clinical history, FA can be classified into IgE-mediated (reactions with acute and rapid onset) or Non-IgE-mediated (reactions that are delayed and non-acute) (NICE, 2011).

The choice of tests that follow to diagnose the FA should be guided by the detailed clinical history, whether that be a skin prick test (SPT) or specific-IgE (sIgE) blood tests. In some cases, an elimination diet of suspect foods may be considered in addition to SPT or sIgE tests (Muraro et al., 2014).

Oral food challenges are usually required to confirm the diagnosis of FA if tests have been inconclusive. The gold standard for oral food challenges is the double-blind placebo-controlled food challenge, where both clinicians and patients are blinded to what the patient has been given. Suspected foods are given in titrated doses to avoid severe reactions, and food challenges are stopped if objective clinical reactions are observed, or the last dose is consumed without a manifestation of clinical symptoms (Muraro et al., 2014).

1.2.3. Management and treatment of food allergy

At present, there is no cure for FA and the current approach towards management of FA is strict allergen avoidance, elimination of the allergen from an individual's diet, and prompt treatment of allergic reactions (Sicherer & Sampson, 2014). Appropriate emergency treatment such as antihistamines or an adrenaline auto-injector (AAI) can also be prescribed (Kim & Sicherer, 2010; Sicherer, 2002; Simons et al., 2011). Clinical management can include both short-term interventions to manage acute reactions, and long-term strategies to minimise the risk of further reaction which can be achieved through dietary modification, education and behavioural approaches, pharmacological and non-pharmacological strategies (Muraro et al., 2014).

A diet based on avoidance of allergens is complex as it requires the patient and their families to have an understanding around label reading, cooking and preventing cross-contamination. It also requires patients and/or their families to communicate the presence of FA to others, such as their friends, family and restaurant and school staff (Annunziato et al., 2015; Kim & Sicherer, 2011; Munoz-Furlong, 2003).

Labelling is an important part of avoiding allergen-based foods as incorrect or ambiguous labelling can lead to accidental exposure (Fiocchi & Martelli, 2006). Current European food labelling laws state that the presence of any major allergen must be stated on the label. However, UK legislation on food regulation states that non-pre-packaged foods do not have to be individually labelled (The Food Information Regulations, 2014). This causes challenges for those diagnosed with FA and has led to a media focus in the UK on FA deaths resulting from inadequate labelling. To add to the complexity, "may contain" labels can be ambiguous and are not a guarantee that the food does or does not contain an allergen. In lieu of the lack of clarity, patients are thus advised to avoid products which are trace-labelled (Boyce et al., 2010).

Cross-contamination not only occurs in factories where food items are produced, but also in everyday locations such as restaurants and schools. In these settings, individuals with FA have to rely on staff to provide allergen-safe foods. A systematic review suggested that between 21 and 31 percent of unexpected allergic reactions had occurred in restaurants (Versluis et al., 2015). Research into the occurrence of allergic reactions at school, identified that 16 to 18 percent of school-aged children with FA were reported to have experienced an allergic reaction at school (Nowak-Wegrzyn, Conover-Walker & Wood, 2001; Sicherer, Noone & Munoz-Furlong, 2001). Staff in restaurants may lack FA knowledge which may contribute to the risks of eating outside of the home. In one study, 38% of restaurant staff believed an individual experiencing a reaction should drink water to dilute the allergen, 23% thought consuming a small amount of an allergen is safe, 21% reported allergen removal from a finished meal would render it safe, 16% agreed cooking food prevents it causing allergy and 12% were unaware FA could be fatal (Bailey, Albardiaz, Frew & Smith, 2011).

In the absence of a cure, research in recent years has focussed on the prevention of developing FA for example, through research into pregnancy diets and early introduction of allergen foods. Studies on pregnancy diets have yielded conflicting results on the likelihood of an infant developing a FA as a result of the mother eating or avoiding allergens (Sicherer et al., 2010; Maslova et al., 2012.) Two studies, the Learning Early About Peanut Allergy (LEAP) and Enquiring About Tolerance (EAT) have investigated whether early introduction of allergenic foods in an infant's diet can help prevent children developing FA. The LEAP study (Du Toit, Roberts, Sayre, Bahnson, Radulovic et al., 2015) involved randomly assigning 640 infants with severe eczema, egg allergy, or both to consume or avoid peanuts until 60 months of age. The primary outcome was the proportion of participants with peanut allergy at 60 months of age, and the findings confirmed that early introduction of peanut significantly decreased the risk of developing peanut allergy among high-risk children. The EAT study (Perkin, Logan, Marrs,

Radulovic, Craven et al., 2016) involved recruiting breast-fed infants at 3 months of age, and randomly assigning them to the early introduction of six allergenic foods (peanut, cooked egg, cow's milk, sesame, whitefish, and wheat; early-introduction group) or to breast-feeding to approximately 6 months of age (standard-introduction group). The prevalence of any FA was significantly lower in the early-introduction group than in the standard introduction group.

1.2.4. The impact of food allergy on children and adolescents

There is a large body of research that has examined the impact of FA in children and adolescents across a range of issues such psychosocial functioning and QoL. It is important to understand the impact felt by children and adolescents with FA, as coping can be an important variable that mediates QoL, psychosocial functioning and adherence (Abbott, 2003).

We know from chronic illness literature, that the stresses associated with chronic ill health and medical conditions in children and adolescents are associated with increased risk for both emotional and behavioural problems and can have an impact on QoL and adherence to medical treatment (Compas, Jaser, Dunn & Rodriguez, 2012). FA is no different, and children and adolescents with FA face complex and substantial lifestyle changes in order to successfully manage their condition (Annunzitao et al., 2015). Food is an integral part of everyday life, and children and adolescents have to cope with everyday stressors and developmental changes as well as cope with the FA, which can place them under increased psychosocial stress and impact their QoL (DunnGalvin & Hourihane, 2016). People with FA must learn to check foods, read labels, and avoid possible contamination of allergens. They must also remember to carry medication and avoid possible allergens. The constant alertness required to avoid allergens, the fear of possible anaphylaxis, and the implications for daily routines and social activities strongly affect well-being in all age groups (DunnGalvin & Hourihane, 2016). Adolescents with FA transitioning to adulthood have additional concerns surrounding their personal life and have reported greater dating anxiety and interference of physical intimacy with partners due to their condition (Hullmann, Molzon, Eddington & Mullins, 2011).

Due to the perceived risk of exposure to an allergen and accidental reaction, FA can lead to social isolation and curtailed social activities that restricts the child or adolescent from socialising with their peers such as during school lunch times, or from attending school trips or birthday parties (Bollinger, Dahlquist, Mudd, Sonntag, Dillinger & McKenna, 2006; LeBovidge, Strauch, Kalish & Schenider, 2009; Noone, Munoz-Furlong & Sicherer, 2003; Sicherer, Noone & Munoz-Furlong, 2001). Two studies conducted in the Netherlands saw a higher absence from school in those with FA possibly due to greater disease burden, whilst a study in the USA found that 10% of parents chose to home-school their children with FA (Bollinger et al., 2006). Both of these scenarios further isolate the child with FA from their peers. Social isolation and restriction can be challenging for adolescents, and research has suggested that social ramifications of FA may have more of an impact on adolescents than the fear of reactions

(Flokstra-de-Blok, DunnGalvin, Vlieg-Boersta, Oude Elberink, Duiverman et al., 2008., Noone et al., 2003). Concerns over being isolated from healthy peers may also stem from feeling different because of their FA. A qualitative study by DunnGalvin, Gaffney and Hourihane (2009) identified that children with FA aged 8 years old reached a transition point whereby they began to describe themselves as different from their peers. In the same study, adolescents described how FA had a strong impact on who they were and the type of friends they chose. Subsequently, this effect on QoL and identity can influence the behavioural responses of children and adolescents such as rejecting the FA identity or refraining from disclosing their FA to others (DunnGalvin et al., 2009).

QoL in children and adolescents with FA can be poorer in comparison to other chronic health conditions and healthy populations. For example, a qualitative study by Calsbeek, Rijken, Bekkers, Dekker and van Berge Henegouwen (2006) in adolescents and young adults aged 12-25 years old identified greater burden of disease, impairment and disruption to daily activities in those with FA than with other chronic conditions such as irritable bowel disease and chronic liver disease. Avery, King, Knight and Hourihane (2003) found that children with peanut allergy reported lower QoL scores than children with Type 1 Diabetes (T1D). In particular, QoL of management of the condition and eating were particularly important and affected in children with peanut allergy, who were more afraid of accidentally eating peanuts than children with T1D were of experiencing a hypoglycaemic event. Physical QoL, QoL in school and overall QoL in children with peanut allergy has also been identified as being significantly poorer than their healthy siblings (King, Knibb & Hourihane, 2009). However, these studies have limitations as they used different measures of QoL, and also very different comparison groups that have symptomatology not necessarily pertinent to those with FA (Valentine & Knibb, 2011). Implications for QoL could therefore differ amongst comparison groups depending on the needs and demands of the illness concerned, and subsequently the coping strategies that could be used to manage these demands.

It is not unreasonable to expect that children and adolescents with FA experience more symptoms of distress or mental health problems compared to a healthy population. The constant care and vigilance required to avoid allergens, and the threat of an allergic reaction can lead to individuals experiencing elevated feelings of distress (Ravid, Annunziato, Ambrose, Chuang, Mullarkey et al., 2012), and increased levels of anxiety and depression have been identified in adolescents with FA (Ferro, Van Lieshout, Ohayon & Scott, 2012; Lyons & Forde, 2004). Social anxiety can be higher in those with FA, than those without (Fox & Warner, 2017) and feelings of anxiety and fear can lead to increased vigilance and checking behaviours or a restriction in interacting with friends, or an avoidance of places with food (DunnGalvin et al., 2009; LeBovidge et al., 2009). Anxiety may also lead to an over-reliance on parents to manage the FA for their child, such as reading food labels or carrying AAIs (Walkner, Warren & Gupta, 2015; King, Knibb & Hourihane et al., 2009; LeBovidge et al., 2009; Manassis, 2012).

Major depression, bipolar disorder, panic disorder and social phobia have also been found to be higher in adolescents (aged 15 and over) with FA than those with no FA (Patten & Williams, 2007).

Interestingly, adolescents with higher health competence (how capable one feels about managing their condition), have been found to have greater levels of anxiety than those with low health competence (Lyons & Forde, 2004). It is possible that anxiety has an adaptive function, as some level of anxiety may lead to better disease management and be protective against risky behaviours (Ravid et al., 2012).

Comparison studies have also found children and adolescents with FA can experience higher levels of anxiety in comparison to those with other chronic conditions such as T1D (Avery et al., 2003) and also greater disruption to daily activities than children with rheumatologic conditions (Primeau et al., 2000). However, the results of these studies are not without criticism. Comparisons between FA and other chronic conditions can be problematic as FA is largely episodic and is not apparent until a reaction occurs, and allergic reactions can have immediate ramifications on health. Primeau, Kagan, Joseph, Lim, Dufresne et al. (2000) collected data on children using parent proxy measures and this also raises issues as to whether relying on proxy measures is a reliable or valid way of assessing a child's FA psychosocial functioning or burden. Parent and child perceptions can differ, and underreporting of internalising symptoms such as anxiety can be common in parents (Ravid et al., 2012; van der Velde, Flokstra-de Blok, DunnGalvin et al., 2011; van der Velde, Flokstra-de Blok, Hamp et al., 2011).

Nonetheless, the evidence to date suggests that psychosocial functioning is affected in children and adolescents with FA. A prospective longitudinal study identified adolescents with FA can have increased levels of generalised anxiety and depression over time and increased levels of disordered eating than those without a FA (Shanahan, Zucker, Copeland, Costello & Angold, 2004). More recent research into the mental health and behaviour of adolescents with FA in comparison to a healthy population by Polloni, Ferruzza, Ronconi, Lazzarotto, Bonaguro et al. (2015), supports this and has also identified that adolescents with FA were more likely to feel greater impact of psychological problems in daily life and internalise their problems more than their healthy counterparts.

However, not all outcomes in those with FA are negative. For example, a qualitative study of adolescents aged 13-16 years old with anaphylaxis found that despite the life-threatening disorder, some felt that anaphylaxis had a relatively low impact on day-to-day life (Akeson, Worth & Sheikh, 2007). In a systematic review, Morou, Tatsioni, Dimoliatis and Papadapoulos (2014) found that whilst children with FA scored worse than children without FA in subdomains including bodily pain, physical functioning, mental health, general health, and emotional, social, and psychological QoL, they performed better in physical health, and had fewer limitations in schoolwork due to behavioural problems. And an assessment of psychological distress among children and adolescents aged 8-17 years old with FA indicated either no differences or lower rates of distress in comparison with normative scores (LeBovidge et al., 2009).

Whilst it is clear that FA presents difficulties in some areas, the findings are mixed. Of course, this may be due to the different self-report instruments used in each study which may make comparisons difficult,

and the time when self-report instruments are administered as children and adolescents may react differently at different points of their illness. However, a further explanation for this may be due to the coping strategies used by children and adolescents to deal with their FA and how these affect their adjustment and reaction to dealing with FA. Research has found that adaptive coping such as assertiveness and organisational skills has led to reduced risk-taking and perceived burden of FA in adults (Peniamina, Bremer, Conner & Mirosa, 2014), and so further research into the types of strategies used by children and adolescents is needed to understand the outcomes observed in FA research.

1.3. Risk-taking in children and adolescents with food allergy

In addition to exploring the effect of FA on QoL and psychological functioning, research has also sought to understand risk-taking in this population. Recent data has suggested that the increase in food-induced anaphylaxis is now occurring more rapidly in the peri-adolescent age period, with increases in visits to hospital emergency departments by children (McWilliam, Koplin, Field, Sasaki, Dharmage et al., 2018; Motosue, Bellolio, Van Houten, Shah & Campbell, 2017), and children and adolescents represent the highest proportion of fatal reactions (Bock, Munoz-Furlong & Sampson, 2001; Pumphrey & Gowland, 2007).

There is debate regarding the explanation of the high rates of morbidity and mortality within this population which may be due to a combination of a discrepancy in medication management and avoiding allergens in foods (Sampson, Munoz-Furlong & Sicherer, 2006). It may also be linked to the transfer from childhood dependence on adults and parents, to the challenges of self-management as an adolescent, as reduced parental observation can lead to a temptation to engage in risk-taking behaviours (Sampson et al., 2006; Monks, Gowland, MacKenzie, Erlewyn-Lajeunesse, King et al., 2010; Gallagher, Worth, Cunningham-Burley & Sheikh, 2012).

Sampson et al. (2006) found that adolescents and young adults aged 13-21 years old ranked concern about FA as lower than concerns for doing well in school, making friends and staying physically fit. They defined a ‘high-risk group’ as those who do not always carry AAI and will eat a food despite it being labelled as ‘may contain’. Interestingly, the high-risk group was not distinguishable by age, sex, or number or severity of reactions. This could suggest that risk may not be specific to either of those factors. However, previous research has identified that boys can take more risks with their health than girls. For example, A study of how adolescents managed diabetes or asthma, found that girls incorporated asthma or diabetes into their social and personal identities and were prepared to inform others and treat themselves in public. On the other hand, boys tended to minimise their illness, particularly in public, leading to possible health-risk consequences (Williams, 2000).

Two quantitative studies (Warren, Otto, Walkner & Gupta, 2016; Warren, Dyer, Ottto, Smith, Kauke et al., 2017) established FA-related risk-taking behaviours in adolescents and young adults aged 13-22 to involve infrequent AAI carriage, adolescents who were less likely to ask about allergenic ingredients

and less likely to believe that they could die from FA. Additionally, Warren et al. (2017), established the importance of social support in risk-taking. Adolescents with greater support from peers, parents and their teachers engaged less in risk-taking behaviour.

In a qualitative study involving focus groups of adolescents (aged 13-16) and young adults (aged 17-21), only 50% of adolescents and 33% of young adults reported carrying an AAI at all times. Occasional ingestion of foods that should be avoided was reported by nearly half of participants in both age groups. Factors that may have increased risk-taking behaviours were attributed to identity, for example, feeling isolated or different, social embarrassment, or being bullied (Sharma, Rand, Matsui, Dowsen, Izenberg et al., 2008).

Whilst some risky behaviour may be developmentally appropriate for teenagers (DunnGalvin et al., 2009) little is known about children with FA who take risks with their health. From the qualitative research conducted by DunnGalvin et al. (2009) children have a natural reliance on parents. This perhaps reduces the opportunity for engaging in risk-taking behaviours. Though DunnGalvin et al. (2009) described the use of 'risky actions' by children as parental control began to wane, it wasn't clear what ages the researchers were referring to in their sample. Additionally, it wasn't clear what exactly 'risky actions' were.

From the research described above, risk-taking in individuals with FA, in particular adolescents, is not limited to ingesting allergenic foods. Risk behaviours identified also included adherence to safely managing one's FA by avoiding allergens and carrying medication (AAIs and/or antihistamines). It is also clear that risk-taking behaviours can be influenced by certain factors in one's life. Together, these different factors go some way to understanding the reasons behind the increased chance of fatalities and allergic reactions in this age group. However, the distinction between those who do and do not engage in risk behaviours may be explained by how individuals cope. It could be possible that some may have developed more adaptive coping strategies to manage risk than others. There is a need to understand the coping strategies of this group and why some individuals, both children and adolescents, may engage in risk-behaviours.

1.4. Coping with long-term conditions in children and adolescents

The study of coping can be derived from psychosocial theories of stress and stress management that describe how individuals manage stressful events or situations (Aalto, Härkäpää, Aro & Rissanen, 2002). Seyle (1991) defined stress as a "non-specific result of any demand upon the body, be the effect mental or somatic" (pg.22). As a result, stress can develop when an individual's existing coping mode and available external resources are inadequate at decreasing tension. Lazarus and Folkman (1984) made a distinction between the different types of stress; harm (referring to the damage or loss that has already happened); threat (referring to the anticipation that harm may be imminent); and challenge (referring to the demands that a person feels confident about mastering).

Long-term conditions, also referred to as chronic illnesses, are medical conditions or health problems that last three or more months, can affect a child's normal activities, result in regular hospitalisations, home health care, and extensive medical care and are unlikely to resolve spontaneously nor are they rarely cured completely (Mokkink, van der Lee, Grootenhuis, Offringa & Heymans, 2008; Stanton, Revenson & Tennen, 2007). Van Cleave, Gortmaker and Perrin (2010) provided a further definition, which is "any physical, emotional or mental condition that prevented him or her from attending school regularly, doing regular school work, or doing usual childhood activities or that required frequent attention or treatment from a doctor or other health professional, regular use of any medication, or use of special equipment" (pg. 624).

Chronic illnesses can present children, adolescents and their parents with both the acute stress of a diagnosis, followed by long-term chronic stress as they begin to adjust to their diagnosis (Compas, Jaser, Dunn & Rodriguez, 2012). Children and adolescents with chronic illness must manage the impact on their emotional life, social life and relationships, their lifestyle, education and self-esteem (Yeo & Sawyer, 2005). Depending on the severity and longevity of the condition, they can experience isolation which can hinder the development and maintenance of friendships resulting in greater dependence on parents (Christie & Khatun, 2012), can be subjected to painful medical procedures, restrictions on activities and even social rejection by their peers (Boekaerts & Roder, 1999; Forgeron, King, Stinson, McGrath, MacDonald & Chambers, 2010). These require continual periods of adjustment as children and adolescents mature and experience changes in their life.

Furthermore, there is evidence that chronically ill children and adolescents experience more stress, distress or mental-health problems than their healthy counterparts. A meta-analysis of 569 studies by Pinquart and Shen (2011), identified that children and adolescents with chronic illness reported significantly higher levels of psychiatric disorder, such as anxiety, depression and aggression than their healthy counterparts. Additionally, cross-sectional studies (Blackman & Gurka, 2007; Blackman, Gurka, Gurka & Oliver, 2011) have identified that children and adolescents with chronic health conditions are more likely to develop emotional, developmental and behavioural problems compared to those without chronic illness. Additionally, the risk of emotional problems has been identified as persisting beyond childhood and adolescence in a systematic review by Secinti, Thompson, Richards and Gaysina (2017). With the impact chronic illness can have on everyday life, as well as on mental health, these present a complex set of stressors that children and adolescents must cope with in addition to coping with the illness itself.

Coping with a chronic illness requires both resources and strategies, and coping strategies are needed to adjust to the stressful situation (Broome-Stone, 2012). Coping has been described as central to the experience of illness, regardless of whether the illness is considered acute or chronic (Turner-Cobb, 2014). When chronic illness occurs in childhood, it presents additional hurdles that the child must overcome at every stage of development aside from regular hospital visits and compliance with

medication. Turner-Cobb (2014) describes these challenges as ones that can affect parental attachment and bonding at the earliest stages of life, to ones that affect regular activities such as sports and games as the child reaches school age. In adolescence, the challenges and difficulties take on a new dimension that includes social pressures and self-consciousness that can impact friendships, relationships and identity.

Adding to the complexity of coping are the differences in coping strategies across the age that have been identified. Younger children have been found to primarily seek support from adults, and increases have been observed in the use of more cognitive coping capacities such as problem-solving and planning in later childhood and adolescence (Zimmer-Gembeck & Skinner, 2011). There is less use of emotional regulating coping strategies such as distraction and relaxation by younger children, suggesting that such strategies are underdeveloped in childhood and possibly acquired during middle childhood (Zimmer-Gembeck & Skinner, 2011).

1.4.1. The role of social relationships on the development of coping

The development of coping responses in children and adolescents can be shaped by social relationships. Therefore, it is important to consider the role of social support on coping, and in particular, the influential role parents play in the development of coping as the family domain provides the earliest context where children acquire strategies to be able to respond and adapt to stress (Bradley, 2007; Power, 2004).

Receiving social support and believing that one has access to strong, quality social support has been shown to be protective factors for individuals across the lifespan (Vellez, Krause, McKinnon, Brunwasser, Feres, Abenavoli & Gillham, 2016) and can be understood as a ‘‘resistance’’ or ‘‘buffering’’ factor in chronic diseases (DunnGalvin & O’Hourihane, 2009).

Seeking social support for stressful situations or for support for one’s emotions are common coping strategies, and has been identified as a positive strategy for managing problems or negative emotions (Compas, Connor-Smith, Saltzman, Thomsen & Wadsworth, 2001; Vellez et al., 2016). Studies have shown that social support can assist with adjustment to chronic disease, demonstrating its utility as an adaptive form of coping. It has also been suggested that different sources of support may differentially affect adjustment (von Weiss, Rapoff, Varni, Lindsley, Olson, Madson & Bernstein, 2002). For example, friends can be an important source of support as they can “buffer” the impact of illness stressors, such as adjusting to chronic disease or coping with difficult medical treatment (Greca, Bearman & Moore, 2002). Early research by Varni, Setoguchi, Rappaport and Talbot (1991) and Varni, Katz, Colegrove and Dolgin (1994) found that classmate support could predict lower levels of depressive symptoms, lower trait anxiety and lower levels of internalising and externalising behavioural problems among children with cancer, and congenital and acquired limb deficiencies. However, in some cases, such as a study by Varni, Wilcox and Hanson (1988) family social support, and not peer support, can be a significant predictor of adjustment in children with juvenile rheumatoid arthritis. DunnGalvin and

O'Hourihane (2009) postulate that these diverse findings may occur because social support needs can differ as a function of a particular disease, and that different dimensions of social support may reflect different dimensions of adjustment.

However, being able to seek out and use social support as a coping strategy, particularly in chronic illness, can depend on whether a child or adolescent chooses to disclose their illness to others. Sharing intimate concerns, fears, and worries is an essential part of friendship for children and adolescents (Greca, Bearman & Moore, 2002). However, in doing so, children and adolescents may be subject to negativity or stigma due to their condition. For some, choosing not to disclose their illness to others, can prevent utilising social support as a means to cope with stressors. Therefore, without adequate support, the demands of illness management can have the potential to complicate psychosocial adjustment to chronic illness (Olsson, Boyce, Toumbourou & Sawyer, 2005).

Parents play an influential role in the shaping of children's coping responses, as the family domain provides the earliest context where children acquire strategies to be able to respond to and adapt to stress (Bradley, 2007; Power, 2004). When a child is diagnosed with a chronic illness, the effects have pervasive consequences for family life, with both immediate and long-term implication of a diagnosis (Christie & Khatun, 2012), and it is difficult to overstate the importance of parents in children's coping (Power, 2008; Skinner and Zimmer-Gembeck, 2007). Parents can determine the stressors that children are exposed to and can themselves become stressors for children. Children may look to parents to understand how to respond to challenges, and thus parents, through their own coping strategies, may contribute to the development of children's coping resources, such as self-efficacy or social skills, and affect their child's adjustment to disease (Monti, Winning, Watson, Williams, Gerhardt, Compas & Vannatta, 2017; Skinner and Zimmer-Gembeck, 2007; Wagner, Chaney, Hommel, Page, Mullins, White & Jarvis, 2003).

Parental perceptions of health and illness can have a profound impact on the way children and adolescents themselves perceive health and illness, risk and how they also interpret disease. As parents are often responsible for helping their children cope in these stressful situations, and chronically ill children and adolescents are largely dependent on their parents for significant aspects of illness behaviour such as how illness symptoms are responded to, or how to manage the stressors and emotions associated with their diagnosis, parents are an important source of support for the chronically unwell child (Monti et al. 2017).

Looking at the parental influences on children's coping more broadly, research has shown that parents can help shape their child's coping strategies in a number of ways. Kliewear, Sandler and Wolchik (1994), suggested three paths by which parents can influence their child's appraisals: modelling, coaching and through contextual paths (Power, 2004). Parental modelling of coping strategies gives the child an opportunity to directly observe how to respond to a stressor and later imitate those responses.

Research by Kliewer, Parrish, Taylor, Jackson, Walker and Shivy (2006) reported associations between maternal active coping with greater use of problem-focused coping in children, and maternal avoidance coping with lower use of problem-focused coping in children. Coaching refers to providing direct instructions on how to appraise an event or threat, which, when recalled, can encourage coping behaviours in children (Miller, Kliewear & Partch, 2010). Contextual effects refer to the ways that parents act as providers and architects in which coping behaviours are learned. For example, children who live in a disrupted family environment, may have more difficulty in learning and using effective coping strategies than children in warm, structured households (Eisenberg, Cumberland & Spinrad 1998; Kliewer et al., 1994).

Unresponsive and insensitive parenting styles may lead to children developing insecure attachments, who may become hesitant and unwilling to explore their environments, and may contribute to the development of avoidant and disengagement coping strategies. Whilst conversely, children who form secure attachments with their mothers are likely to develop and use more adaptive coping strategies (Contreas, Kerns, Weiner, Gentzler & Tomich, 2000). Furthermore, parents own anxiety and distress will have implications for how their children cope (DunnGalvin & Hourihane, 2009). For example, overprotectiveness over their child to ensure their safety can stunt children's social and emotional development (DunnGalvin & Hourihane, 2009), and by shielding their children from stress, parents may also be preventing children from developing effective and adaptive coping strategies (Fox, Henderson, Marshall, Nichols & Ghera, 2005; Skinner & Zimmer-Gembeck, 2007). Parents with depressive symptoms may be less available to support their child in managing stress, and may be less responsive and more disengaged from their child (Brenning, Soenens, Braet & Bal, 2012; Lovejoy, Graczyk, O'Hare & Neuman, 2000). This was also identified in a longitudinal study by Monti, Rudolph and Abaied (2014) who found that depressed mothers were less likely to suggest adaptive coping strategies, such as cognitive restructuring, to their children.

Therefore, to understand the types of coping strategies demonstrated by children and adolescents with chronic conditions, it is important to hold in mind the role that social systems play in the development and utilisation of coping strategies.

1.4.2. Models of coping in paediatric research

Research into coping with long-term conditions in children and adolescents has found that this population use a variety of coping strategies. These strategies are often described in the context of the models of coping that underpin that research. The Transactional Model of Stress and Coping (TMSC) (Lazarus & Folkman, 1984), and the Approach-Avoidance model of coping (Roth & Cohen, 1986), are two models of coping that have been widely used in research with children and adolescents with chronic illness.

The Transactional Model of Stress and Coping

The Transactional Model of Stress and Coping (TMSC) (Lazarus & Folkman, 1984) is one of the most frequently cited and applied theories of coping in research with children and adolescents despite the fact that it was developed for adults (Compas, Jaser, Dunbar, Watson, Bettis et al., 2014). According to Lazarus and Folkman (1984), coping strategies are cognitive and behavioural efforts to manage specific internal or external demands that are appraised as being taxing or exceeding the resources of the individual. This model views coping as an interactive transaction between the individual and their environment and between cognition and emotion. This model theorises that the appraisal of stress influences how individuals cope with the stressor and describes two forms of appraisal that takes place which can be influenced by personal and contextual factors. Primary appraisal involves an evaluation of the stressor or threat the individual is currently facing, followed by secondary appraisal which evaluates the different coping strategies and resources, and the controllability of the threat or stressor. Following these two stages of appraisal, an appropriate coping strategy is chosen. Coping is divided into two overarching strategies: problem-focused and emotion-focused. Problem-focused coping aims to act on the stressor, and, can include strategies such as information seeking, generating a list of solutions and changing the circumstances that created the stressor. Emotion-focused coping aims to control the negative emotional response(s) to the stressor, and, can include strategies such as emotional expression, seeking social support and avoidance.

Research on a range of chronic illnesses, such as T1D and chronic pain, suggests that problem-focused coping tends to be associated with better adjustment, fewer depressive symptoms and better clinical/medical outcomes (e.g., metabolic control in T1D) (Edgar & Skinner, 2003; Jaser & White, 2011; Compas, Boyer, Stanger, Colletti, Thomsen et al., 2006). Problem solving as a means of coping has been found to be the most important determinant for positive psychosocial functioning in adolescents with conditions such as asthma and eczema (Meijer, Sinnema, Bijstra, Mellenbergh & Wolters, 2002). Conversely, emotion-focused coping strategies, such as avoidance and wishful thinking, have been shown to be related to poorer metabolic control, QoL and depression in children and adolescents with T1D and chronic pain (Graue, Wentzel-Larsen, Bru, Hanestad & Sovik, 2004; Jaser & White, 2011; Kashikar-Zuck, Vaught, Goldschneider, Graham & Miller, 2002).

Approach-Avoidance Coping

Roth and Cohen's (1986) Approach-Avoidance model of coping works similarly to the problem-focused and emotion-focused concepts of the TMSC and comprises two coping styles – approach or avoidance. In fact, parallels between the approach-avoidance and problem-focused and emotion-focused constructs can be drawn as these two models of coping are quite similar. The goal of approach-coping strategies is to change the nature of stressor through strategies such as information seeking or closely monitoring the stressor. Avoidance-coping strategies are used to repress, ignore, or orient oneself away from the stressor (Bernard, Cohen, McClellan & MacLaren, 2004). The efficacy of the model is related to perceived

controllability and duration of the stressor. For example, uncontrollable stress could be best managed through avoidance coping, whilst approach coping is more suited to controllable stress (Bernard, Cohen, McClellan & MacLaren, 2004). Avoidant strategies can be useful in that they may reduce stress and prevent anxiety from becoming crippling. On the other hand, approach strategies can allow for an individual to take appropriate action or noticing and taking advantage of changes in a situation that might make the stressor more controllable (Roth & Cohen, 1986).

Research applying this model of coping has shown that avoidance coping can be associated with poorer asthma-specific adjustment (Ezop, 2002) and poorer metabolic control and more depressive symptoms in T1D (Graue, Wentzel-Larsen, Bru, Hanestad & Sovik, 2004; Jaser, Faulkner, Jeon, Murphy, Delamater & Grey, 2012). Avoidance coping has also been associated with poor adherence to a gluten-free diet in children with coeliac disease (Wagner, Zeiler, Grylli, Berger, Huber et al., 2016). In contrast, approach coping styles yields more positive outcomes such as better metabolic control or better psychosocial adjustment in youth with T1D (Jaser, Faulkner, Whittemore, Jeon, Murphy et al., 2012).

1.4.3. Control-based model of coping

Though the models described above have been widely applied to research conducted with children and adolescents with long term conditions, the use of such theories has been argued to be inappropriate as they were developed to account for adult coping processes and could therefore be considered developmentally unfriendly as they do not provide clear theoretical links to other developing subsystems such as cognition or language (Skinner & Zimmer-Gembeck, 2007). Additionally, the use of models such as the TMSC and the approach-avoidance model is argued to have oversimplified coping into two factors, i.e. problem-focused vs. emotion-focused, approach vs. avoidance. Such models may hide the diversity of the different coping responses used by children and adolescents (Turner-Cobb, 2014). Additionally, it has been argued that a single coping strategy could encompass both problem-focused and emotion-focused coping styles. This has been illustrated by Compas, Connor-Smith, Saltzman, Thomsen and Wadsworth (2001) with an example of an individual walking away from an argument which could serve as both the emotion-focused goal of calming oneself down, and the problem-solving goal of using the time to generate alternative solutions to the conflict (pg. 92).

Though two-factor models such as the TMSC remain widely used in coping literature, the field has moved to categorise coping into more sophisticated groups. One such model is the control-based model of coping (CBMC), proposed by Compas et al. (2001), which has been applied to paediatric research across a range of chronic illnesses such as diabetes, chronic pain, and cancer. They define coping as ‘conscious volitional efforts to regulate emotion, cognition, behaviour, physiology, and the environment in response to stressful events or circumstances’ (pg. 89). After reviewing a number of factor analytic studies of coping in children and adolescents, they concluded that a three-factor model of coping

adequately reflects the nature and structure of coping in children and adolescents. This three-factor model of coping comprises:

- Primary-control coping: This involves efforts to change a stressor by directly *engaging with the stressor* with coping strategies such as using problem-solving or social support. Or through efforts to change the *emotional reaction to a stressor*, with coping strategies such as emotional expression or emotional modulation, such as by letting people know how they feel or keeping feelings under control (Connor-Smith, Compas, Wadsworth, Thomsen & Saltzman, 2000).
- Secondary-control coping: This involves efforts to *adapt to stress*, by engaging with one's emotions concerning the stressor, and includes coping strategies such as cognitive reappraisal, positive thinking, acceptance and distraction. For example, telling oneself that everything will be alright, thinking that something good will come from a situation, or realising that one has to live with things the way they are (Connor-Smith et al., 2000).
- Disengagement coping: This involves efforts to *steer away* from the stressor and one's emotions, and can include coping strategies such as avoidance, wishful thinking, or denial. For example, staying away from people or things associated with the stressor or trying to forget about the stressor (Connor-Smith et al., 2000).

Application of this model in coping literature has shown that primary-control coping strategies are related to better quality of life and lower HbA1c values in children and adolescents with T1D, whilst secondary-control coping has been associated with better quality of life but not related to lower HbA1c levels (Jaser & White, 2011). Cognitive restructuring, a form of secondary-control coping, has also been associated with less depression and greater positive well-being (Edgar & Skinner, 2003).

Secondary-control coping such as acceptance and cognitive reappraisal, has also been associated with lower levels of symptoms of anxiety and depression (Dufton, Dunn, Slosky & Compas, 2011; Hocking, Barnes, Shaw, Lochman, Madan-Swain et al., 2011), whilst disengagement coping, such as denial, has been associated with high levels of anxiety and depression, as well as higher somatic symptoms in chronic pain samples (Compas et al., 2006; Thomsen, Compas, Colletti, Stanger, Boyer & Konik, 2002). Interestingly, primary control coping was found to be associated with higher levels of pain which may largely be due to the perceived uncontrollability of the pain itself (Compas et al., 2006). This could suggest that secondary control coping strategies may be more effective in uncontrollable situations, than primary control coping strategies.

In comparison, in paediatric cancer, disengagement strategies, such as avoidance, were found to be associated with poorer adjustment, and higher levels of anxiety and depressive symptoms (Miller, Vannatta, Compas, Vasey, McGoron et al., 2009), whilst secondary control coping strategies were negatively related to symptoms of anxiety and depression (Miller et al., 2009; Compas et al., 2006; Compas et al., 2014).

There is evidence to suggest that coping responses are not universally effective or ineffective, and Compas et al. (2012) postulate that the degree to which a coping strategy leads to better or worse emotional outcomes may be dependent on the match between demands of the stressor, and the goals and nature of the coping response. They further discuss the role of controllability which may be central in understanding how children and adolescents cope with health and illness related stressors. Perceived or actual controllability of the stressor may be crucial in determining the efficacy of certain coping strategies used. Children and adolescents with chronic illness experience a number of stressors that can be unanticipated and uncontrollable. This may be important for children and adolescents with FA, as allergic reactions can sometimes be unpredictable, for example, the severity or occurrence of the reaction despite taking care to avoid the allergen, which can make management of FA and adherence to self-care behaviours difficult (Jones, Smith, Frew, du Toit, Mukhopadhyay & Llewellyn, 2014).

The decision and rationale for using the CBMC in this thesis lies within the limitations of two-factor models of coping such as the TMSC, and crucially with the development and application of the CBMC model in paediatric healthcare research. I considered the use of existing two-factor models of coping, such as the TMSC, which has been widely used in research with children and adolescents, and debated the distinction between the problem-focused and emotion-focused constructs of the TMSC, and whether this would be suitable for children and adolescents with FA. Further researching both its utility and criticisms associated with that model, my concerns echoed that of Compas et al. (2001) regarding the structure of two factor models which can be broad and at times confounded when specific coping behaviours can straddle both emotion-focused and problem-focused components. Furthermore, Compas et al. (2001) argued that many disparate types of coping strategies can be placed within these categories. For example, emotion-focused coping can include relaxation, seeking emotional support, emotional suppression, and self-criticism.

In agreement with Compas et al. (2001), I was unsure of using a model such as the TMSC which does not account for strategies indicative of disengagement coping strategies as a sole component, rather that strategies such as avoidance of social situations, can be attributed to either problem-focused or emotion-focused coping categories. I was concerned that the use of such a model would oversimplify the types of coping strategies identified in children and adolescents with FA, and be unable to accurately represent a problem-focused or emotion-focused coping strategy.

Due to its applicability across a range of paediatric illnesses as evidenced by research conducted by Compas et al. (2012), this is a developmentally appropriate model which would be suitable for the population studied in this thesis. With the limitations and criticisms of two-factor models of coping such as the TMSC which may oversimplify coping strategies, the CBMC may be more suitable as a valid measurement model to understand coping with FA in children and adolescents and warrants further investigation.

1.5. Coping with food allergy

As previously discussed, individuals with FA have to deal with a variety of stressors to ensure their safety, such as carrying medication and avoiding allergen foods. There is also the effect on QoL and psychological functioning that adds to the challenges that those with FA must cope with.

Sampson et al. (2006) conducted a quantitative study with adolescents and young adults aged 13-21 to understand risk-taking behaviours and coping strategies via an anonymous Internet survey. Results from the survey indicated coping behaviours broadly identified as carrying and using emergency medication such as their AAI, reading food labels and communication. Only 61% of the sample carried their medication at all times, with the rest reporting variability with regards to medication carriage. There was also variability in the frequency of reading food labels, with 15% reporting that they only read labels for food they had never eaten before. Interestingly, 58% of the sample avoided foods that were labelled 'may contain'. Only 61% of the sample indicated that all their friends and peers knew about their FA, whilst 6% had not disclosed their FA to anyone. Whilst this provided insight into the coping strategies of this population, this study did not explicitly differentiate the use of these strategies between age groups, making it difficult to establish whether the coping strategies of younger participants differed to older participants. Additionally, it didn't explain how children below the age of 13 cope. Whilst this study set out to investigate coping strategies, there was an absence of a coping model to explain these findings, nor a standardised measure of coping to identify these strategies.

In a pilot study examining coping and posttraumatic stress symptoms (PTSS's) in children and adolescents aged 7-13 years old, Weiss and Marsac (2016) found that coping strategies included a combination of cognitive restructuring, avoidance, and social support. Though no statistically significant differences were found for type of coping based on a history of PTSS's, effect sizes suggested possible differences may be found with a larger sample size, with those with significant PTSS's using more coping strategies of each type. Whilst this study used a standardised measure, the 'How I Coped Under Pressure Scale", limitations lay in data collection which took place immediately after a food challenge, a possibly stressful time for children which may have influenced the responses given.

Another quantitative study by Polloni, DunnGalvin, Ferruzza, Bonaguro, Lazzarotto et al. (2017) explored the links between coping strategies and alexithymia, a personality construct described as 'a lack of words to express emotions' (pg. 1055), and anxiety in adolescents and adults aged 14-32 years old. Avoidance coping strategies had the highest contribution in explaining alexithymia, whilst those with higher alexithymia were found to use avoidance coping more than other strategies, such as problem-solving and positive thinking. Whilst the Coping Orientation to Problems Experienced-New Italian Version Inventory was used to assess coping responses, the broad age range presents problems in differentiating between the coping strategies of younger verses older participants. A series of multivariate analyses of variance were conducted to explore differences and associations between

subgroups including age group but did not look at the differences of the types of coping strategies used between age groups. Additionally, this study does not explore how children below 14 years old cope.

Literature where coping is not the primary focus do provide further context and understanding of how this population copes. Such literature has explored self-care behaviours that are indicative of coping, such as carrying and using AAI's, to more exploratory qualitative research that focuses on the experiences of living with FA and how FA is managed. Studies of the use of AAIs such as by Gallagher, Worth, Cunningham-Burley and Sheikh (2011) and Macadam, Barnett, Roberts, Stiefel, King et al. (2012) have shown that like Sampson et al. (2006), there can be variability in the rate of AAI use and carriage. Barriers to using an AAI in adolescents ranging from 12-19 years old included external factors, such as location, burden or carriage and knowledge of AAI's (Gallagher, Worth, Cunningham-Burley & Sheikh, 2011; Macadam et al., 2012). A quantitative study by Jones, Llewellyn, Frew, DuToit, Mukhopadhyay & Smith (2015) found that social support by means of a patient support group was associated with good adherence behaviours in a cross-sectional study of adolescents aged 13-19 years old with FA. Whilst these studies provide understanding behind the use/non-use of AAIs and adherence to self-care behaviours, they only provide insight into one aspect of coping. Furthermore, children below the age of 12 years are not included in any of these studies.

DunnGalvin et al. (2009) found that coping strategies fell on a continuum ranging from generalised/avoidant, adaptive to minimisation/risk strategies in a qualitative study of children and adolescents aged 6-15 years old with FA. Avoidant strategies included avoidance of places associated with food to more generalised avoidance, and avoidance strategies were divided into those that were used to manage risk/emotions (e.g. anxiety) and those that were used to manage identity, both social and personal. Adaptive strategies were identified as positive emotional, cognitive or behavioural strategies used to cope with the everyday experience of living with FA. Children whose parents encouraged independence and self-management were more likely to describe using these positive coping strategies, such as informing others of their FA. Minimisation strategies included cognitive minimisation, such as rejection of FA identity and 'risky' actions such as forgetting the AAI on purpose. Such strategies were used by children, in particular boys, who had experienced bullying or teasing. Younger children were also found to rely more on their parents that older children and adolescents. Whilst this study described the coping strategies in younger children as well as adolescents, there was an absence of the application of a coping model to explain these findings.

Another qualitative study that explored how adolescents managed their FA, also identified behaviours indicative of coping. Monks et al. (2010) found that whilst adolescents aged 11-18 years old would carry their medication, avoid allergens and read food labels, there were also barriers to appropriate FA management, such as a lack of knowledge around when to use an AAI and social circumstances such as places that were not familiar to them.

As described in section 1.4, coping strategies can be shaped by social relationships. Parents, in particular, play an influential role and parental distress, threat perception and coping strategies can reflect how children respond to and manage FA. (DunnGalvin & O'Hourihane, 2009). Children and adolescents can restrict disclosing their FA to others, only mentioning it if needed, due to concerns over a lack of understanding of others and social embarrassment (DunnGalvin et al. 2009).

Whilst collectively, these studies go some way to explaining how children and adolescents cope, there is still a lack of literature where coping is the primary focus. Studies that do explore coping as their primary research focus lack a theoretical basis of coping that can categorise these behaviours. Furthermore, the use of standardised coping measures to identify strategies varies amongst difference studies. Meanwhile, studies that explore the experiences of living with or managing FA provide insight into the behaviours that are indicative of coping, but only provide limited insight into how children and adolescents cope that may be limited to a particular behaviour, such as carrying and using AAIs. As such, we still do not fully understand how children and adolescents with FA cope with their condition.

1.6. Measurement of coping - the role of patient reported outcome measures and a case for a food allergy specific measure

Outcome measures have a necessary role both in research and in clinical practice as they can provide an objective measurement of the outcome being studied. Outcome measures in healthcare have traditionally focussed on physiological markers, such as blood pressures and test results. However, there has been a shift from a reliance on physiological measures, to measurement of functional status, health perception, patient-reported experience measures (PREMs) and patient-reported outcome measures (PROMs) (Flannery, Glew, Brewster & Christie. 2018). These outcome measures complement traditional clinical outcomes of morbidity and mortality, by capturing the patient's perspective regarding their health and its treatment (Butt, 2016).

PROMS are important as they gauge a patient's view of their own health that is directly reported by the patient without interpretation of the patient's response by a clinician and have become accepted as an important component of outcomes research (Pesudovs, Burr, Harley & Elliott, 2007; Devlin & Appleby, 2010; Weldring & Smith, 2013). The use of outcome measures provides a means to track symptoms and function over time and can provide both the clinician and the patient with a way of visualising necessary information about their functional status and well-being (Johnson, 2008).

The use of PROMs to measure functional status and wellbeing through the patients' own reports is widespread within paediatric healthcare settings. And whilst validated and widely used PROMs for physical health and mental health exist, the challenge lies in how to capture outcomes in a meaningful way that takes into consideration the complex interplay of physical and mental health for children and adolescents living with a chronic health condition (Flannery et al., 2018).

Research that has investigated how children and adolescents cope with chronic illness have used a variety of measures of coping, and a number of measurement scales for coping have been developed. A review of selected measures of stress and coping by Blount, Simons, Devine, Jaaniest, Cohen, et al. (2008) set out to identify the most frequently used assessment instruments within a paediatric population. Within their review, they identified twelve instruments that assess coping that include both generic and specific measures of coping (Table 1.2). With a range of coping instruments available, it is important to understand why an illness-specific coping measure has more utility compared to a generic measure of coping such as those listed in Table 1.2.

Table 1.2: Coping instruments and descriptions, adapted from Blount et al. (2008)

Coping instrument	**Description & Population**
Adolescent Coping Orientation for Problem Experiences (A-COPE) (Patterson & McCubbin, 1987)	Self-report for ages 11 and up.
Coping Response Inventory – Youth Form (CRI-YF) (Ebata and Moos, 1991)	Self-report for ages 12-18.
Coping Strategies Inventory (CSI) (Tobin, 1991)	Self-report for ages 7 and up. Parent report for children aged 3 and up.
Kidcope (Spirito, Stark & Williams, 1988)	Self-report for ages 7-12 and 13-18.
Role-Play Inventory of Situations and Coping Strategies (RPISCS) (Quittner, Tolbert & Regoli, 1996)	Self-report adolescent version; self-report school-age children version; self-report parents of adolescent's version; self-report parents of school-age children version.
Ways of Coping (revised version) (WOC) (Folkman & Lazarus, 1980)	Self-report for children, adolescents and adults.
Pain Coping Questionnaire (PCQ) (Reid, Gilbert, & McGrath, 1998)	Self-report for ages 8 and up. Parent report.
Pain Response Inventory (PRI) (Walker, Smith, Garber, & Van Slyke, 1997)	Self-report for school-age children (RAP).
Waldron/Varni Pediatric Pain Coping Inventory (PPCI) (Varni et al., 1996)	Self-report for ages 5–12 and 13–18. Parent version (for children aged 5–18 years).
Behavioral Approach–Avoidance and Distress Scale (BAADS) (Hubert et al., 1988)	Observational rating scale of ages 3–13 years.
Child Adult Medical Procedure Interaction Scale (CAMPIS) and (CAMPIS-R) (Blount et al., 1998; Blount et al., 1997)	Observational rating scale of ages 6 months to 13 years.
Child Adult Medical Procedure Interaction Scale-Short Form (CAMPIS-SF) (Blount et al., 2001)	5-point rating scale. Could be used with both children and adults.

Though generic measures can provide the "common currency" that allows for comparisons across different patient groups, they can miss important aspects of health status or changes in health that are specific to the condition being investigated (Devlin & Appleby, 2010). McKenna (2011) argued that generic measures do not allow for valid comparisons to be made between the impacts of different

diseases, or between healthy and diseased populations, and postulated that generic PROMS no longer have a clear role in measuring health outcomes. A further concern raised by McKenna (2011) is that generic measures are not designed to capture areas of concerns to specific patient populations. This could lead to the inclusion of items that are irrelevant to certain patient groups or condition or the exclusion of issues that are a specific feature or concern of the disease under study. Disease or condition specific instruments can address the aspects of outcome that are important for a particular patient population or condition by only asking questions that are relevant, meaningful and acceptable to them. Additionally, a further positive of specific measures lies in the potential for showing differences between competing therapies if patients are receiving treatment. (McKenna, 2011).

Nonetheless, generic coping scales, such as the Kidcope and Ways of Coping questionnaire have been widely used in paediatric research. For example, Edgar and Skinner (2003) and Yi-Frazier, Yaptangco, Semana, Buscaino, Thompson et al. (2015) have used the Kidcope in their research with adolescents with diabetes, and Graue et al. (2004) used a modified version of the WOC also with adolescents with diabetes. However, because of the complexity of demands placed on children and adolescents with chronic illness, Compas et al. (2012) argued that it is important to be precise about the types of stress that are the targets of the patient's coping efforts. They further postulated that careful specification and measurement of the aspects of an illness and its treatment that present stressors and challenges to children and their parents is required, as each condition is unique.

It is these stressors that are unique to a condition that has been the basis of opinions surrounding the development and use of disease specific scales. For example, Alto et al. (2002) developed an asthma specific coping scale, arguing that scales developed for chronic illnesses in general do not capture all relevant coping behaviours, and that certain coping challenges may be specific to an illness. In FA research, disease specific scales for FA have been developed, most notably the Food allergy Quality of Life questionnaire (FAQLQs), a QoL questionnaire for children, adolescents, adults and parents of children with FA, and the Food Allergy Independent Measure (Flokstra De Blok et al. 2008). The FAIM is an independent measure used in the construct validity of the FAQLQs to demonstrate that the FAQLQs were measuring only that part of QoL affected by FA and not general quality of life aspects. It is based on an independent measure developed by Oude Elebrink, de Monchy, Golden, Brouwer, Guyatt et al. (2002) to validate a QoL questionnaire for patients with yellow jacket allergy. The FAIM was later validated by van der Velde, Flokstra-de Blok, Vlieg Boerstra, Oude Elberink, DunnGalvin et al. (2010)

Whilst generic measures have been used and continue to be used in paediatric research, there is a consensus and support for disease-specific measures. With regards to FA QoL scales, Flokstra De Blok et al. (2008) argued that a disease specific QoL measure would be more sensitive than a generic QoL measure, further highlighting the need for FA specific measures. With a FA specific coping measure, items would be tailored around the unique stressors and challenges attributed to FA and be more

meaningful to the children and adolescents with FA completing it. It would also help researchers and clinicians to understand how children and adolescents with FA cope. DunnGalvin, Polloni, Le Bovidge, Muraro, Greenhawt et al. (2018) have since developed a preliminary FA coping and emotions scale for children, adolescents and young people aged 6-23 years old. However, this scale has been developed using secondary data analysis, which can have limitations. This is further discussed in Chapter 6.

1.7. Summary

This introductory chapter has introduced the reader to the two key topics of this thesis; FA and coping. It has highlighted the impact of FA on children and adolescents, as well as the challenges experienced by this population living with this condition. This chapter introduced the concept of coping in children and adolescents with long-term conditions, and the theoretical perspectives of coping that have been applied to research in this area. Models and theories of coping have moved beyond the simplified notions of 'problem-focused' versus 'emotion focused' to more sophisticated groupings as proposed by the CBMC (Compas et al., 2001). As demonstrated by its application to other chronic illnesses, it may be the most appropriate model to explain coping in children and adolescents with FA. This chapter also discussed the measurement of coping and the role PROMs have in paediatric health research. Though a range of generic measures exist and continue to be used in coping research, disease-specific scales are preferable as they are tailored to the specific nuances of the condition and will capture these nuances in a way generic measures would be unable to.

Whilst there is a substantive body of literature that explores children and adolescents' experiences of living with FA, such as the psychosocial and QoL issues associated with FA management, there is a lack of FA research where coping is the primary focus. Coping is an important mediating variable between life stressors and psychological adjustment, and can influence adherence to treatment (Abbott, 2003). With the complexities surrounding FA management and the effects living with FA can have on the individual, there is a need to understand how children and adolescents with FA cope, and what influences their style of coping. As coping strategies can differ with age (Hampel & Petermann, 2005; Zimmer-Gembeck & Skinner, 2011), it is important to understand any age-specific coping strategies used by children and adolescents with FA. To date, there is no study that has attempted to investigate in-depth how children and adolescents cope with FA, and more precisely, no studies exist within the FA literature that have used a CBMC as the theoretical underpinning.

Without a clear understanding of how children and adolescents with FA cope, we are unable to fully understand the effects of FA on other domains of life, such as psychological functioning or QoL. Additionally, no studies have researched coping in this population using a validated, disease-specific coping measure that is focused on the unique stressors and challenges of FA; such a measure may help identify the coping strategies used by this population in research. In the absence of a FA specific coping measure, there is a need to develop such an instrument to help illustrate how this population copes.

1.8. Aims and objectives for this research

At present, not enough is known about how children and adolescents cope with FA, nor has there been any FA specific coping measure developed to further understand this issue. Therefore, the following aims and objectives have been developed for this thesis:

- To systematically review literature examining how children and adolescents cope with FA.
- To explore how children cope with their FA and understand the context within which these coping strategies are identified.
- To explore how adolescents cope with their FA and understand the context within which these coping strategies are identified.
- To develop and validate a FA specific measure of coping.

As current FA research where coping has been the primary focus has lacked a theoretical foundation to explain coping in children and adolescents, the CBMC (Compas et al., 2001) will provide the framework to understanding the coping strategies used in this population.

CHAPTER 2 Research methodology, methods and data analysis

This chapter presents the methodological foundation of the thesis, provides an overview of the different research paradigms, outlines the rationale for the epistemological position of pragmatism adopted, and the use of mixed methodology to undertake the programme of research reported. This chapter also presents the research designs, methods and data analysis techniques that will be used.

2.1. Aims and objectives of the research

The aims and objectives of this thesis are to explore children's and adolescents' experiences of coping with a FA, and to use this data to inform, develop and validate a coping scale for this population using the guidelines of Pesudovs, Burr, Harley and Elliott (2007). This thesis consists of four empirical studies that utilise either qualitative or quantitative research methods.

The first three studies focus on an exploration of coping in children and adolescents with a FA. The final study involves the development and validation of a Coping Scale for Food Allergy (CS-FA).

- Study 1. To systematically review existing studies that have examined coping behaviours in children aged 6-19 with a food allergy.
- Study 2. To explore how children (aged 8-11 years old) cope with a food allergy.
- Study 3. To explore how adolescents (aged 12-16) cope with a food allergy.
- Study 4. To develop and validate the Coping Scale for Food Allergy.

2.2. Comparing paradigms

In order to answer the research question proposed in Chapter 1 and undertake the four empirical studies in this thesis, I had to consider what methods would be appropriate for each study. However, there are differences in the theoretical perspectives and paradigms on which both qualitative and quantitative research are based (Todd, Nerlich, MckEown & Clarke, 2004; Yardley & Bishop 2008).

By definition, a paradigm is defined as a "set of interrelated assumptions about the social world which provides a philosophical and conceptual framework for the organised study of that world" (Filstead, 1979, p.34). Historically, qualitative research is associated with either "interpretative" or "constructivist" paradigms, whereas quantitative research is associated with "scientific" or "positivist" paradigms (Yardley & Bishop, 2008). These different approaches are argued to be incompatible as ways to study the social world due to the differences of both ontology (*what* we may know) and epistemology (*how* we know what we know) (Dures, Rumsey, Morris & Gleeson, 2011).

When designing a research proposal, Crotty (1998) suggested four questions that researchers should consider:

1. What methods do we propose to use?
2. What methodology governs our choice and use of methods?
3. What theoretical perspective lies behind the methodology in question?
4. What epistemology informs this theoretical perspective?

At the start of this thesis, I reflected on these four questions when deciding upon the appropriate methodology for each study and considered the different epistemology and ontology of both qualitative and quantitative research methods. In the following sections I outline these paradigms, and the assumptions associated with each approach.

2.2.1. Positivist approach (quantitative)

The positivist approach is traditionally dominant in psychology, and adopted, by default, in quantitative research (Yardley & Bishop, 2017). Researchers who apply a positivist paradigm employ quantitative and empirical measures that can test hypotheses, which can lead us to believe "the world as made up of observable, measurable facts" (Glesne & Peshkin, 1992, p. 6). Indeed, the ontological perspective of positivists is that there is only one true reality that is objective, measurable, predictable and controllable (Dieronitou, 2014).

From the epistemological perspective, positivists argue that the scientific method is a way of "achieving the most accurate possible observations", by using controlled environments that eliminate the multiple sources of variability present and use of precise measures to avoid inaccuracies that can be associated with any subjective impression (Ponterotto, 2005; Yardley & Bishop, 2017). As such, positivist (quantitative) methods can have high levels of internal validity, and strong, causal inferences can be drawn from them (McGrath & Johnson, 2003).

2.2.2. Constructivist approach (qualitative)

In the latter half of the twentieth century, the possibility of 'objective knowledge' was increasingly challenged by the view of knowledge as a way of perceiving and relating to the world as being shaped by pre-existing concepts and shared assumptions (Yardley & Bishop, 2017). In contrast to the positivist viewpoint, the ontological perspective of constructivists is that reality is subjective, constructed in the mind of the individual and their socio-cultural experiences, rather than it being an externally singular "true" entity (Hansen, 2004, Yardley & Bishop, 2017). Our awareness of the world is guided by our particular subjective and socio-cultural experiences, and it is therefore argued to be impossible to separate the assumptions and values that form an individual's identity and guides their activity (Yardley & Bishop, 2017).

Because of this, constructivists believe it is impossible to achieve the positivist view of 'objective knowledge' and argue that controlled, experimental, study of behaviour is artificial because it strips the individual of agency and social context which gives behaviour meaning (Yardley & Bishop, 2017). Self-

report measures may prevent respondents from expressing an alternative or contradictory viewpoint, impose the researcher's conceptions on their viewpoints and scientific psychological research can create unnatural situations that have minimal relevance into how participants operate in non-experimental contexts (Yardley & Bishop, 2017).

Qualitative methods focus on a hermeneutical and interpretative approach, which theorises that meaning is hidden and must be brought to the surface through reflection by the researcher and participant during their interactive dialogue, and their interpretation (Ponterotto, 2005). The researcher is viewed as the "co-producer" of knowledge and requires the researcher to be reflexive and critically aware of their work (Biggerstaff, 2012).

2.2.3. Pragmatism, post-positivism & logics of inquiry

Both pragmatism and post-positivism have been argued to be significant influences on the modern mixed methods movement (Giddings & Grant, 2007). Pragmatism, as a philosophical basis, has been suggested as a framework that has the potential to encompass both qualitative and quantitative approaches in a way that doesn't compromise the integrity of the method. It also addresses the concerns of both qualitative and quantitative researchers by emphasising that all human inquiry involves imagination, and interpretation, intentions and values must also necessarily be founded in empirical, embodied experience (Yardley & Bishop, 2017). A pragmatist's aim of inquiry is to achieve a better and richer human experience, rather than a truth that is independent of the human experience through a combination of methods that best answers the aim of the inquiry.

The early pragmatist John Dewey stressed that creative pragmatic inquiry should bring to light the conflicting interests and ideologies of the different paradigms, and question what influences the aims of research and what we understand as "good" and "true" (Yardley & Bishop, 2017). Despite the difference between qualitative and quantitative research in both their methods of inquiry and in their validation, from the pragmatists' perspective there is no fundamental contradiction between the basic objectives and the characteristics of these two paradigms (Yardley & Bishop, 2008).

Positivism has been criticised for ruling out various sources of the ways in which we understand the world, including those deriving from human experiences, reasoning or interpretation as inappropriate for scientific enquiry. Positivism, however, has been argued to be pragmatic in its approach, since only testable hypotheses are considered able to generate reliable knowledge. In addition to positivism is the post-positivist epistemologies and ontologies (Fox, 2008). Understanding, rather than explanation, is viewed as the objective of the post-positivist enquiry, and the concept of the absolute truth seen as an aspiration rather than something that can be discovered "once and for all" and postpositivist scientific thinking has increasingly abandoned any conception of verifying absolute truth (Fox, 2008; Yardley & Bishop, 2017). It is perfectly possible to use quantitative methods with a constructivist perspective, provided that the researcher is reflexively aware of and open about the way in which the findings of the

research are influenced by the assumptions and constraints of the research methods used (Yardley & Bishop, 2017).

An alternative approach to the qualitative/quantitative debate proposes that there are differences between qualitative and quantitative approaches that go beyond that of the type of data being collected (Hiles, 2014). Hiles argues that the focus should be on understanding the *logic of inquiry*, before considering the methods of data collection and the subsequent analysis. Hiles explained that there are three logics of inquiry to illustrate the relationship between theory and data: (i) deduction, (ii) induction and (iii) abduction. Deduction is concerned with testing the prediction of data (findings) from theory, typically associated with quantitative research. Induction is concerned with generating theory from the data obtained, using "inductive inference", such as that of qualitative research. Finally, abduction is concerned with the explanatory relationship between theory and data and finding the "best explanation" of the data.

2.3. Mixed-methodology research and its applicability in health psychology

The use of qualitative and quantitative research methodologies often produces debate regarding whether such methodologies can be combined and used together. The methodological difficulties of combining the two, stems from the profound differences between the theoretical perspectives and paradigms on which each method is based. Hiles (2014) argues that despite the challenges, there are no irreconcilable epistemological differences between both qualitative and quantitative research methods. Rather, there are many advantages to combining the two methods as they each complement what the other lacks, and knowledge is increased in a manner that is more meaningful than either method could achieve alone (Creswell & Plano Clark, 2011). For instance, quantitative methods have high levels of 'internal validity' (McGrath & Johnson, 2003), achieved through the use of precise and replicable measures, and strictly controlled experimental conditions. However, it can be argued that the cost of this is a decrease in 'external validity' – that which corresponds to conditions in everyday life (Yardley & Bishop, 2017). Conversely, qualitative research sacrifices control and it can be impossible to isolate the effect on a particular factor, particularly in hypothesis testing (Yardley & Bishop, 2017). Therefore, the combining of the internal validity of quantitative methods, with the external validity of qualitative methods can be a useful way of adopting a mixed methods approach (Yardley & Bishop, 2017).

Health psychology research aims to understand the role of psychological factors in the human experience of health and illness (Dures et al., 2010). It has been suggested that the adoption of mainstream psychology methods has resulted in the reliance of quantitative research designs that are isolated from real world contexts (Dures et al., 2010) and this approach cannot reflect the realities of people's experiences of illness and health care environments (Crossley, 2000). Marks (2006) suggested that if psychological research on health and illness is to be viewed as ecologically valid and replicable, there

requires an increase in the ecological validity of studies, using multiple levels and methods that are complemented by qualitative studies to explore experiences of health and illness. Thus, the flexibility of mixed methods is well suited to the aims of the thesis, and the field with which this thesis is grounded in.

The research presented in this thesis was conducted using a pragmatist position, adopting a mixed methods approach. By taking a pragmatic approach, I was given the freedom to identify and select research methods that met the aims of each empirical study (Creswell & Plano Clark, 2011), rather than through my preference of a certain methodology. Due to the aims of the research of exploring how children and adolescents cope with FA, and to develop and validate a coping scale, a mixed-methodology approach was therefore deemed the most appropriate methodology to use as both detailed qualitative and quantitative research methodology was required. Additionally, the use of mixed methods counteracted the disadvantages of using a single research method, as highlighted by Creswell & Plano Clark (2011).

2.4. Rationale for research design and methods

2.4.1. Systematic review

The first study I conducted as part of this thesis was a systematic review. A systematic review is a summary of literature that uses "explicit and reproducible methods to systematically search, critically appraise, and synthesise on a specific issue" (Gopalakrishnan & Ganeshkumar, 2013). There are advantages and disadvantages to conducting systematic reviews. Early work by Mulrow (1994) emphasised the worth of using systematic reviews in healthcare research as they can efficiently integrate existing information, establish if scientific findings are consistent and can be generalised across populations, settings and treatment variations, or if findings vary in particular subsets. Advantages also lie in the scientific strategies used in systematic reviews that can ensure future replicability and minimise the bias that may be visible in more traditional literature reviews where a systematic or explicit method is not applied for the search, selection and analysis of data (Perestelo-Perez, 2013). Furthermore, systematic reviews are considered the best evidence for getting a definitive answer to a research question (Gopalakrishnan & Ganeshkumar, 2013).

However, despite the rigorous methods applied into conducting searches for the proposed research question, there is inevitable subjectivity in the screening process of potentially relevant studies. There can be flaws in the selection of studies and loss of information on important outcomes. And despite the steps taken to minimise bias, publication bias could lead to distorted findings if papers reported statistically significant results which were more likely to get published and cited, and therefore identified and included in reviews (Egger, Dickersin & Davey Smith, 2001).

Despite these disadvantages, systematic reviews use a precise question to produce evidence to underpin a piece of research. Additionally, as a stand-alone piece of research, systematic reviews should be

conducted prior to undertaking further research (Robinson & Lowe, 2015). As I had a specific research question of how children and adolescents coped with their FA, a systematic review was considered more appropriate in answering my research question in order to provide a foundation for the research thereafter, than a traditional literature review which is typically more general in its approach (Robinson & Lowe, 2015). Although there was a possibility of bias and subjectivity during the screening and selection process of potentially relevant studies, by using a structured approach of PRISMA, any potential bias was minimised through transparency and structure.

2.4.2. Semi-structured interviews

After completing my systematic review, I conducted semi-structured interviews as a way of exploring how children and adolescents coped with their FA in more detail, and to build upon the findings of the systematic review. Additionally, the data obtained from semi-structured interviews was used to generate items for scale development.

Interviewing is the most common method of data collection in qualitative research (Jamshed, 2014), and can be conducted individually or in groups. There has been some debate regarding the value of focus groups over individual interviews when conducting research with children. For example, focus groups can provide rich data that is produced from the interaction between group members which individual interviews cannot achieve (Kennedy, Kools & Krueger, 2001). Additionally, by participating in focus groups, children and adolescents can have the opportunity to hear the opinions of others (Heary & Hennessy, 2006).

However, there are advantages to conducting individual semi-structured interviews over using focus groups. Semi-structured interviews are valuable as they allow researchers to explore subjective viewpoints and specific ideas with particular individuals, and gather in-depth accounts of people's experiences (Denscombe, 2003; Evans, 2018). The use of a schedule can help to guide an interview, but also allow for other relevant themes and topics to develop (Choak, 2012). It also allows researchers to exert greater control over the interview process in contrast to the "unpredictable nature of group interaction" (Heary & Hennessy, 2006. Pg.59). Individual interviews can also provide a confidential and private setting and as such, may be more conducive in allowing children and adolescents to disclosing details of their lives that they may not feel comfortable doing in a group setting (Heary & Hennessy, 2006).

With the advances in technology, individual interviews are no longer only conducted in a face-to-face setting, and the Internet is now an increasingly popular method of gathering qualitative data. This gives the ability to overcome issues around remote participants and efficiencies in time and cost (Bolderston, 2012; Evans, Elford & Wiggins, 2008). Skype has been used as a new research medium that gives the additional benefit of enabling the 'visual' in an interview setting and can, to an extent, remain a face-to-face experience (Bolderston, 2012).

For the purposes of the qualitative research set out in Chapters 4 and 5, individual interviews were preferred and selected over the use of focus groups. Firstly, participants were to be recruited nationwide, rather than from a specific part of the country, which would have presented complications in setting up focus groups because participants located in different parts of the United Kingdom would have had difficulty attending a focus group. Thus, individual interviews were considered more convenient for the purposes of data collection and allowed the child and adolescent to be in control of where and when they would participate. Giving children and adolescents the option of being interviewed over Skype not only had practical benefits around the scheduling of interviews and last-minute changes but allowed children and adolescents across the United Kingdom to take part in a study that may have been unavailable to them if only face-to-face interviews were being conducted and travelling to the interview challenging or impossible.

Another rationale for using individual interviews lies within the broad age range of the participants in chapters 4 and 5. The qualitative research in this thesis set out to explore how children and adolescents aged 8 to 16 years old cope with a FA. Conducting a focus group with this age range may have posed some difficulties in cultivating discussions around coping with FA, particularly if older participants were facing different life experiences from younger participants. In a review of using focus groups in paediatric health research, Heary and Hennessy (2002) emphasised that focus groups should contain children who are broadly similar in age based on differing cognitive abilities and sensitivities of children of different ages depending on topic. However, as setting up focus groups could be challenging for the reasons above, the use of individual interviews was deemed the most appropriate method of collecting data.

2.4.3. Developing the interview schedule

The questions for the interview schedule were based upon a combination of the findings of the systematic review (Chapter 3), and consultation with experts in paediatric allergy, health psychology and child development. The interview schedule acted as a guide of questions and prompts to facilitate conversations that explored how children and adolescents coped with their FA, and what facilitated the types of strategies that were used, or not used. Following a review of literature in child and adolescent chronic health management, additional questions regarding management of FA in social situations where parents were not present were included. Interview questions were reviewed regularly with the supervisory team before finalising to ensure the questions would capture how children and adolescents would cope with their FA in different scenarios and were also easy to understand given the broad age range of participants.

2.4.4. Scale development

As described in Chapter 1, PROMs have become accepted as an important component of outcomes research (Pesudovs et al., 2007). PROMs can provide a means for measuring treatment benefits by

capturing concepts related to how a patient feels or functions with respect to their health or condition (U.S Dept. of Health and Humans Services FDA Centre for Drug Evaluation and Research, 2006). As coping challenges may be specific to an illness, a generic coping measure may not capture all relevant coping behaviours of a particular illness in comparison to an illness specific scale (Aalto et al, 2002), and therefore a coping scale specific to FA would help to overcome the disadvantages of using a generic coping measure. Therefore, after analysing the interview data, I developed a coping scale for children and adolescents with FA.

Guidelines for the development of PROMS have been produced by the U.S Dept. of Health and Humans Services FDA Centre for Drug Evaluation and Research (2006) (FDA), Pesudovs et al. (2007) and more recently by Carpenter (2018) who proposed ten steps in scale development and reporting (Appendix 1). These guidelines include generating items in consultation with the patient population either through focus groups or interviews and a literature review, conducting a pilot test with analyses such as factor analysis to provide justification for removal of items, and assessing for reliability and validity by testing against appropriate measures or between groups. In order to develop a scale using best practice procedures, the guidelines of Pesudovs et al. (2007) and Carpenter (2018) were followed for the development of the coping scale. Items were generated through the findings of the systematic review and qualitative interviews with children and adolescents aged 8-16 years old with FA. The scale was then tested by the intended population, and appropriate analyses conducted for the removal of items and testing for reliability and validity.

2.4.5. Scale reliability and validity

In order to assess the performance of the instrument, validity and reliability must be measured. Pesudovs et al. (2007) advise that the population completing the pilot scale should be broad and representative of the target population. In order to meet this recommendation, questionnaires were distributed using online and hardcopy methods. Hardcopy questionnaires were distributed by the allergy clinics at Sandwell and West Birmingham NHS Trust and the questionnaire was also uploaded online and the link to the online questionnaire advertised through social media by the charity Allergy UK to widen the scope of participation beyond children and adolescents at allergy clinics. This had an advantage of reaching a wider population of children and adolescents beyond those seen at the allergy clinics at Sandwell and West Birmingham NHS Trust and increasing external validity of the scale as it could be generalised to a wider population of children and adolescents with FA.

Using questionnaires in research has advantages such as being relatively quick to administer, and the capacity to collect large amounts of data and reach out to a larger population (Fargas Malet et al, 2010). However, return rates can be low due to a variety of factors, including literacy levels and whether participants find the questionnaires “irrelevant or difficult to complete” (Hill, 1997, pg. 175). To minimise issues relating to literacy or the irrelevance of questions, children and adolescents who

participated in the semi-structured interviews were invited to 'review' the scale through a cognitive interview. Cognitive interviews are used in scale development to inform item revision decisions which can be based on test content such as clarity or relevance of items, and response process involved in responding to an item (Dumas, Watson, Fragala-Pinkham, Haley, Bilodeau et al., 2008; Castillo-Díaz & Padilla, 2013). Using "think-aloud" procedures and verbal probes, respondents are asked to describe their thoughts either concurrently as they answer each question, or retrospectively after completing the scale (Peterson, Peterson & Gilmore Powell, 2017). There are considerations when conducting cognitive interviews with children and adolescents for the purpose of PROM development. Patel, Jensen and Lai (2016) recommend setting the child's expectations about the process of the cognitive interview prior to starting, for example, by explaining that the interview is to make the questions better and easier to understand for others. Patel et al. (2016) also stipulate that asking younger children to rephrase questions may be too cognitively demanding, and questions such as "what is the question asking?" may be better understood than "what does the question mean?". Children and adolescents were asked to go through each question on the scale and discuss with me if the items were easy to understand, what they thought the questions asked and whether they felt it was relevant to someone with a FA. In addition to conducting cognitive interviews, the scale was also reviewed by a panel of experts comprising paediatric allergists, clinical and health psychologists and experts in child development to ensure items were relevant to this population.

To aid with response rates, participants who requested hardcopies of questionnaires were provided with a stamped, self-addressed envelope so no charges would be incurred by the participant to return the questionnaire. Participants who completed a hardcopy questionnaire or a questionnaire online, were also made aware of approximately how long it would take to complete the questionnaires, so they were prepared for the amount of time they would have to give to complete them.

2.5. Participant sampling

The primary aim of this thesis was to examine the coping strategies of children and adolescents aged 8 to 16 years old. Firstly, this age group was selected to enable exploration of coping in children of both primary and secondary school age, whilst ensuring that children were old enough to take part in interviews and complete questionnaires themselves, rather than by parental proxy. Kortesluoma, Hentinen and Nikkonen (2003) posited that children aged 7 to 11 years old can produce more information about their experiences than children below the age of 7. However, analysis by Varni, Limbers and Burwinkle (2007) on self-report data by children aged 5 to 16 years old, identified that children as young as 5 years old can reliably and validly self-report their health-related QoL if given the opportunity to do so with age appropriate instruments. Nonetheless, the lower age limit of 8 years old was selected, as research conducted by Helseth and Slettebø (2004) has identified that children above the age of 7 years old have the ability to reflect on and understand what happens in their lives (Helseth and Slettebø, 2004). The upper age limit of 16 was chosen as although adolescence has been defined to

include young people up to the age of 25, the experiences of those over the age of 16, such as social demands, will be markedly different and can exacerbate the challenges of both studying and treating young people (Jaworska & Macqueen, 2015). Secondly, it was also important to focus on this age range as recent data has suggested that the increase in food-induced anaphylaxis is now occurring more rapidly in the peri-adolescent age period, with increases in visits to hospital emergency departments by children (McWilliam et al., 2018; Motosue et al., 2017), and the highest proportion of deaths from anaphylaxis occurs in adolescence (Bock et al., 2001; Pumphrey & Gowland, 2007).

For the systematic review, to avoid omitting any important studies that could contribute to answering the research question, the age range was extended to include participants aged 6 to 19 years old following an initial scoping search which identified that potentially relevant articles included participants of this age range.

For the semi-structured interviews and scale development, a purposive sampling method was employed, and participants were children and adolescents aged 8-16 years old with a clinical diagnosis of FA. Participants were recruited through advertising at paediatric allergy clinics in Birmingham and nationally via the social media channels of Allergy UK (who co-funded the PhD). This increased the range of participants beyond the West Midlands, which was beneficial for the applicability of the findings at a wider population level. As participants were not recruited from the same clinic, this increased the chance of participants having different experiences of their allergy care that could lead to varied responses and experiences.

Anderson (1991) suggests that participants should be acknowledged and that there should be a means to 'reimburse' them. Though rewarding can be a contentious issue as it could be construed as an incentive, leading to accusations of bias, it is acceptable if the researcher feels it is the right thing to do (Whiting, 2008). Children and adolescents being interviewed were giving up a considerable amount of their free time (lasting up to one hour or more) after school or at a weekend and were therefore given a £10 book voucher as a 'thank you' for taking part. Additionally, children and adolescents who completed the coping scale and validation questionnaires were entered into a prize draw to win £50 of book vouchers to thank them for their time.

2.6. Rationale for the choice of data analysis

2.6.1. Systematic review

The data from the systematic review was analysed using a narrative synthesis approach as it can draw together broad knowledge from a variety of methodologies and approaches (Popay, Roberts, Sowden, Petticrew, Arai, Rodgers et al. 2006). Thematic Analysis (TA), which is a process of reading key texts and refining the findings into key themes, was used to identify commonalities amongst the data following the guidelines of Braun and Clarke (2006). Unlike other qualitative approaches, such as meta-ethnography, TA tends towards summarising the data rather than developing theory (Bearman &

Dawson, 2013). For the purpose of the systematic review to identify how children and adolescents coped with FA, TA was the most appropriate form of analysis to help identify the commonalities reported by the authors. Braun and Clarke (2006) detail the six phases to conducting TA (Figure 2.1).

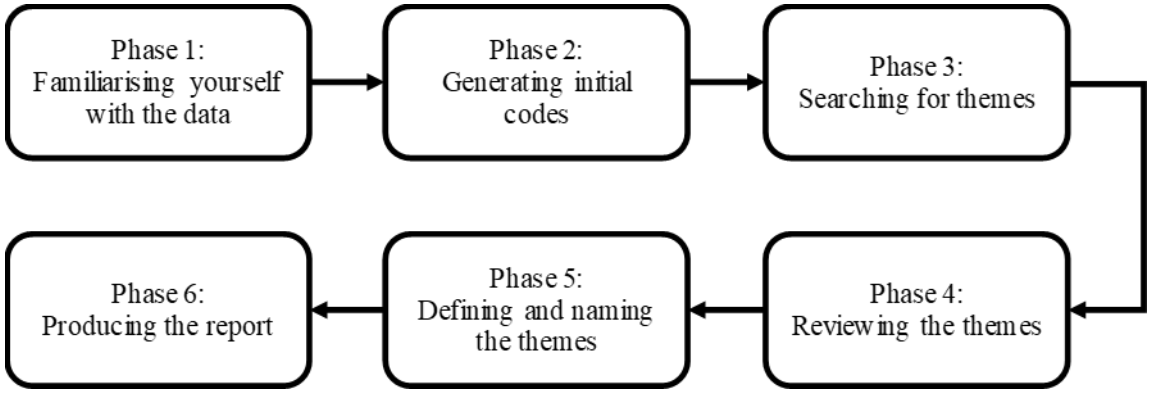

Figure 2.1: The six phases of conducting thematic analysis, adapted from Braun and Clarke (2006)

Phase 1 involves familiarisation with the data, when any patterns and ideas may begin to emerge. Following this, codes are generated and applied to the transcripts (Phase 2). Coding can be "data driven" (inductive) and open in the beginning so as not to be influenced by existing theory, rather coding based on the meaning that emerges from the data. Coding can also be "theory driven" (deductive) using the theoretical underpinnings of the phenomena studied. Codes that are similar are organised together to identify any commonalities, and once a theme is identified, relevant codes are allocated to that theme (Phase 3). Following this process, the initial themes are reviewed and renamed, and compared against coded text passages from the interviews to check that the themes represents the content. Any additional data or codes can be allocated to a theme if it was missed at an earlier screening stage or did not fit within its original theme or code (Phases 4 and 5). The write up of the results of the TA make up Phase 6 of Braun and Clarke's guidelines. Disagreement regarding themes were discussed with the supervisory team. This involved discussions around the interpretations of the qualitative data, how these interpretations were formed and what the themes within the TA represented.

The results presented in the included studies were coded and analysed by applying Hiles' (2014) logic of inquiry, using induction, deduction and abduction to the TA. Abduction was introduced by the pragmatist and philosopher Charles Peirce (1903) who argued that by not considering the notion of abductive reasoning, our understanding of deductive and inductive reasoning will be undermined (Hiles, 2014). The use of an inductive 'bottom-up' approach in qualitative work has been championed to prioritise the participants voices, whilst the deductive 'top-down' method has focused on hypotheses (Shaw, Smith & Giles, 2018). Abductive analysis, on the other hand, engages in a two-way dialogue between data (inductive) and established theory (deductive) (Hiles, 2014; Shaw, Smith & Giles, 2018).

Hiles (2014) stressed the importance of the 'exploratory' process of explanatory inference in abductive reasoning, and the importance of abduction for qualitative data analysis. As the aim was to draw together

a range of constructs to explain and apply context and meaning to the data had been obtained, abductive analysis was therefore adopted.

Data was initially coded inductively, obtaining information from the data itself. This was then followed by deductive coding, using the CBMC (Compas et al., 2012) as the theoretical basis to categorise coping strategies that had been identified. Finally, abductive reasoning was adopted during the analysis in all three studies, which involved a recurring process of mapping the inductive main codes and sub-codes against the deductive codes of the components of the CBMC. Further information about the analysis for each study can be found in the relevant chapter of this thesis.

2.6.2. Interview data

Data collection for the interviews was an on-going process. A purposive sampling method was applied, and I used a sampling frame to ensure that there was a fairly even number of males and females across the age group with a range of FA. This sampling method allowed me to continue to interview participants until data saturation, which can be defined as the "point in data collection and analysis when new information produces little or no change to the codebook" (Guest, Bunce & Johnson, 2006, pg.65) was reached. To help determine whether saturation had been reached, I made notes after each interview summarising what had been discussed with the participant. I was able to refer back to these notes after subsequent interviews to check if there was any new data emerging, or if saturation had been reached.

During the analysis, it was clear that coping strategies differed depending on the age of the child, whether the child or adolescent was attending primary or secondary school, and the autonomy associated with adolescence, such as socialising without parents. Therefore, the age groups were split into two groups: 8 to 11 years old and 12 to 16 years old. I then conducted separate analyses for the 8-11-year olds (Chapter 4) and the 12-16-year olds (Chapter 5). Similar to a developmental review by Zimmer-Gembeck and Skinner (2011), developmental differences were identified between these age groups, such as the difference in the amount of social support used in younger children and the difference in level of independence in adolescents, which further justified the separate analyses conducted.

The interview data, like the systematic review, were also analysed using TA following the guidelines of Braun and Clarke (2008) detailed in section 2.6.1. TA was selected over other qualitative analysis approaches such as grounded theory, or interpretative phenomenological analysis (IPA) due to its flexibility in its applicability to both realist and constructionist paradigms, and its ability to provide detailed and minimally organised accounts of data (Braun & Clark, 2006). It was also chosen due to the purpose of the research, which was to identify the commonalities of how children and adolescents coped, rather than their experiences of being allergic to food where IPA may have been more suitable. Like that of the systematic review, disagreement with regards to themes were dealt through discussions with the supervisory team around interpretation of the quotes obtained from the interviews and what the themes represented.

Similar to analysis of the systematic review (section 2.6.1), Hiles' (2014) logic of inquiry using induction, deduction and abduction was used. The interview data was initially coded inductively and followed by deductive coding using the CBMC (Compas et al., 2012). Finally, abductive reasoning was adopted to aid the development of key themes. Further information about the analysis can be found in the relevant chapters of this thesis.

2.6.3. Reliability in qualitative research

Qualitative research requires a different kind of scrutiny to assess for reliability and rigour to that of quantitative work. Qualitative research can also be criticised for lacking scientific rigour due to a lack of transparency, the analytical procedures used, and researcher bias influencing findings (Noble & Smith, 2015). As there is no universal consensus on how this can be judged, demonstrating rigour can be challenging (Rolfe, 2006).

Malterud (2001) described the specific challenges that could be faced by qualitative research; that of reflexivity (the effect of the researcher on the data), and transferability (findings that can be shared and applied to other settings). Reflexivity was defined by Mays and Pope (2002) as data that has been shaped or influenced by the prior experience or assumptions of the researcher. They also stipulated that the research process and such biases should be made clear as part of any qualitative report. Finlay (2006) argued that qualitative research could never be exactly replicated as, for example, what emerged from an interview could be due to the approach of the interviewer, the interviewer-participant relationship and/or the context of the interview itself. There are those who take an antirealist approach and argue that qualitative research represents a "distinctive paradigm" and therefore cannot be judged by conventional measures of validity, generalisability and reliability (Mays & Pope, 2000,). Realists on the other hand argue that it is possible to assess qualitative research against criteria that is common to both qualitative and quantitative research – that of validity and relevance (Mays & Pope, 2000, pg. 51).

In an attempt to ensure validity, the methods of data collection and analysis interpretation were made as transparent as possible for the systematic review and semi-structured interviews. For example, the development and review of the codes and themes from the analyses was reviewed between the researcher and the supervisory team.

In an attempt to ensure transferability in the qualitative research of Chapters 4 and 5 where semi-structured interviews were conducted, steps were taken to ensure that sampling strategies were purposeful and relevant to the research question (Malterud, 2001) and a purposive sampling method was applied to recruit children and adolescents within the age group with a FA. Children and adolescents were recruited both locally through the allergy clinics in the Sandwell and West Birmingham NHS Trusts, and nationally via the allergy charity Allergy UK.

I participated in a continuing and regular process of reflexivity by discussing the interview process and any emerging data with the supervisory team. This was particularly important during the first set of

interviews to ensure that the participants were able to understand the types of questions being asked, and whether the content of the interview schedule was appropriate or required any adjustment with wording. It also allowed for discussions regarding creativity during the interviews, or how to navigate difficult scenarios such as when participants began to express boredom, or how to approach asking difficult questions that could be upsetting. This process of including the views and opinions of other researchers during data collection and analysis is known as triangulation, and although it can be met with controversy as a test of validity, triangulation can be used as a way of ensuring comprehensiveness and encouraging reflexive analysis of the data (Mays & Pope, 2002). I also kept a reflective diary to reflect upon my personal experiences of conducting the research and analysing the data.

2.6.4. Scale development - Factor analysis and factor extraction model

I used a variety of methods to assess internal and external reliability and validity of my coping scale. Factor analysis was used to assess internal structural validity which is a statistical method that reduces a large set of variables into smaller and manageable number of dimensions or components. It is not only useful in reducing data but also in the development of instruments, and there are two main approaches– exploratory (EFA) and confirmatory (CFA) (Pett, Lackey & Sullivan, 2003; Pallant, 2011). A basic assumption of EFA is that a set of underlying factors exist within a collection of observed variables and is used when researchers do not know how many factors are necessary to explain the interrelationships among a set of items. On the other hand, CFA, is used to test specific hypothesis or theories and can be used to test the underlying dimensions of a construct identified through EFA. As EFA is the most appropriate method for scale development, EFA was used to reduce the variables within the coping scale, examine the interrelationships of items and identify the underlying components.

The term factor analysis encompasses a variety of different techniques that are related. Two popular techniques are principal components analysis (PCA) and factor analysis (Pallant, 2011). PCA is a widely used method and is appropriate when the purpose is to reduce the number of items to a smaller number of representative components with all of the variance in variables being used. In contrast, factor analysis only includes the common variance in the extraction which is analysed (Beavers, Lounsbury, Richards, Huck, Skolits et al., 2013; Pallant, 2011). The choice between factor analysis and PCA has been subject to some debate (Gaskin & Happell, 2014). Factor analysis can provide a solution that is uncontaminated by unique and error variability, and one that more accurately represents data in the real world (Gaskin & Happell, 2014). However, Tabachnik and Fidell (2007) state that if an empirical summary of dataset is the goal, PCA is appropriate. In this thesis, PCA was used in order to retain as much of the scale's variance as possible.

2.6.5. Determining the number of factors to retain

There are a number of methods that can assist with determining the number of factors to retain. A common technique is Kaiser's criterion, using the eigenvalue rule. This rule stipulates that only factors

with an eigenvalue of 1.0 or more are retained. However, this method has been criticised as it can result in the retention of too many factors and the possibility of over-dimensionalisation (van der Eijk & Rose, 2015). The scree test (Catell, 1996) involves plotting each eigenvalue of the factors and identifying a change in the shape of the curve and can help identify the number of factors to retain. However, subjectivity in interpretation can make it an unreliable procedure (Kanyongo, 2005).

Garrido, Abad and Ponsoda (2013) provided evidence that parallel analysis (PA) should be performed using PCA as the method of extraction. This involves comparing the size of the eigenvalues with those obtained from a randomly generated set of data of the same size, and then retaining eigenvalues that exceed the corresponding values from the random dataset (Pallant, 2011). This method has been identified as the most accurate in identifying the correct number of components to retain in comparison to Kaiser's criterion and the scree test (Pallant, 2011).

As PA has been found to be more accurate in identifying the number of factors to retain, this method was applied, with PCA as the method of extraction. This was done whilst holding in mind the possibility of over-dimensionalisation and Kaiser's eigenvalue rule, and adopting an exploratory approach recommended by Tabachnik and Fidell (2007) to experiment with different numbers of factors until a satisfactory solution was found.

2.6.6. Testing for validity and reliability

Reliability assesses whether the instrument is consistent at measuring the same construct over different administrations (Pesudovs et al., 2007). Reliability can be explored within two categories, through single administration, or multiple administration such as a test re-test. Internal consistency was assessed using Cronbach's alpha for the total scale and the factors identified by the PCA. Acceptable values of alpha range from 0.70 to 0.95 (Tavakol & Dennick, 2011) however, Field (2009) proposes a maximum alpha value of 0.90 to prevent redundancy. However, it is not advised to over emphasise the Cronbach's alpha value as a measure of reliability, and that other methods such as test-retest should be conducted (Pesudovs et al., 2007). During the test-retest, retested participants should be in a "stable" condition (Paiva, Barroso, Carneseca, de Pádua Souza, dos Santos et al., 2014) so as not to affect the data obtained. In addition to assessing the Cronbach's alpha, the final scale underwent a second test of reliability through a test re-test with participants who had not experienced an allergic reaction or hospital attendance over a two-week period.

Validity demonstrates that an instrument measures the construct that it was intended to measure and relates well to other similar measures (Pesudovs et al., 2007). There are different types of validity that need to be considered. Construct validity examines whether the instrument measures the construct it purports to measure, in the case of this research, the construct being "coping". Construct validity includes convergent validity and discriminant or divergent validity (De Vellis, 2011). To look for convergent validity, the new instrument should correlate with another that measures a related construct.

To assess convergent validity, I conducted Pearson correlation coefficients with the following validated scales: KIDCOPE, Revised Children's Anxiety and Depression Scale (RCADS), the Brief Illness Perception Questionnaire (B-IPQ), Food Allergy Quality of Life (FAQLQ) and the Food Allergy Independent Measure (FAIM). Further descriptions on the selection of these scales can be found in Chapter 6.

Discriminative validity assesses the scale's ability to discriminate between different groups (De Vellis, 2011). To assess this, I conducted tests of differences such as t-tests and ANOVA's to distinguish between gender, age group, number of allergies and hospitalisation following a reaction. Testing between these groups were selected, as research has shown that coping strategies or coping styles may be affected by such factors.

For example, research has found that younger children tend to seek support from adults, or use distraction coping strategies, whilst problem-solving strategies have been observed in later childhood and adolescence (Hempel & Petermann, 2005., Zimmer-Gembeck & Skinner, 2011). Gender differences in coping has been observed, for example, Eschenbeck, Kohlmann and Lohaus (2007) found that boys would use avoidant coping strategies more than girls who were found to use social support and problem-solving coping strategies.

Whilst there has yet to be research that has conclusively studied associations between multiple FA and coping strategies in children and adolescents, the negative effects of multiple FA on QoL and psychosocial functioning in this population has been documented, with poorer QoL scores shown in this group (Wassenberg, Cochard, DunnGalvin, Ballabeni, Flokstra-de Blok et al., 2012). Coping strategies therefore may differ depending on the impact having multiple FA has on QoL or psychosocial functioning, which may in turn influence the types of coping strategies used. For example, diabetes studies have shown that active coping is associated with better QoL, in comparison to avoidant coping which is associated with worsening QoL (Jaser & White, 2011).

Finally, to my knowledge, no study has looked at the associations between coping strategies and hospital visits following an allergic reaction, although there is research that has looked at the association between hospital visits and QoL in mothers of children with FA (Cummings, Knibb, Erlewyn-Lajeunesse, King, Roberts & Lucas, 2010). However, research that has focused on different chronic illnesses, has shown an association between certain types of coping strategies with hospitalisation. For example, asthma studies have shown that avoidant coping strategies are associated with hospitalisation, whilst active coping strategies are a protective factor against hospitalisation (Adams, Smith & Ruffin, 2000). Therefore, it is possible that there is an association between the coping styles of children and adolescents with FA and hospital visits following an allergic reaction.

2.7. Ethical considerations

Prior to conducting any research with children and adolescents, all studies in this thesis received NHS and HRA ethical approval. As the research in this thesis involved the participation of children and adolescents, there were ethical considerations that differ from conducting research with adults for both qualitative and quantitative studies.

2.7.1. Ethical considerations of conducting qualitative research with children and adolescents

Kirk (2007) raised three ethical issues when conducting qualitative research with children. That of "power relations", "informed consent" and "confidentiality.

Power relations can be an issue if a child or adolescent participant does not feel free to refuse to participate in a study, withdraw from the research process, or share their own views and experiences (Kirk 2007). Informed consent should always be freely given by children and adolescents who can make an appropriately informed decision to take part (Fargas-Malet, McSherry, Larkin & Robinson,2010). The use of information leaflets, tapes, letters and oral presentations to explain the research project to children, their parents/carers can be useful to ensure that children and adolescents are adequately informed to decide and give consent to participate (Fargas Malet et al., 2010).

I developed age-appropriate information sheets about the study for all prospective participants, and their parents, and gave them my contact information in case they had any questions about the research. Prior to conducting the interview with the participant, both the parent and participant gave informed consent by signing consent forms. I always asked participants if they wanted to continue taking part, and that they could withdraw before the interview had begun as a way of ensuring that they did not feel pressured into taking part by their parents. Throughout the research process, I regularly reminded participants that they were able to withdraw at any point of the research process and that their data and information would be destroyed.

Whilst children and adolescents should be informed that their information will be kept confidential, they should also be made aware about the limitations of confidentiality before they participate in research, so that they are able to give fully informed consent (Williamson, Goodenough, Kent & Ashcroft, 2005). This could be by informing them that if they disclose abuse or indicate that they are coming to harm or danger that confidentiality may need to be breached in order to safeguard their welfare. Prior to starting any interview, I reminded participants about confidentiality and what this meant, and when confidentiality may need to be breached such as if they disclosed any information that indicated that they were at risk of harm. At the end of the interview, I debriefed participants about the study, reminded them what would happen with their data and reminded them about confidentiality. I then asked about how they felt about the interview and whether any aspects of the process or questions asked made them feel upset or distressed, or if they had any further questions about the study itself. The website address

and contact details of Allergy UK were available to participants or their parents if they requested any advice.

Other considerations researchers should make when conducting qualitative research with children and adolescents include the context, location and nature of the research taking place, as these could affect what is discussed with the researcher (Fargas Malet et al., 2010). The location or setting is important and could affect privacy and confidentiality (Mauthner, 1997; Barker & Weller, 2003). For example, if conducting interviews in a child or adolescents' home, finding a private and quiet space may be problematic due to child protection issues, and if parents or carers wish to be present, they may influence the responses of the child (Barker & Weller, 2003; Scott, 2000). A "neutral" setting is advised for data collection if possible, to enhance consistency and stability of situations factors unless otherwise appropriate (LeCompte & Goetz, 1982; Patel, Jensen & Lai, 2016). In Chapters 4 and 5, children and adolescents were given the option to choose the location of the interview. A "neutral" setting was offered at Aston University, if they preferred this over their homes. However, in cases where the University was not accessible to participants, and Skype was the preferred method of interviewing, a discussion was made with the parents prior to the interview about allowing the child a private and quiet space in which they could participate in the interview alone without any distraction from family members, and to ensure they felt comfortable about speaking to the researcher.

Finally, to help establish rapport with child or adolescent participants before an interview, Cameron (2005) advises the use of "free narrative" which can help settle the participants, as well as allow the interviewer to grasp the participant's communication style. This can help ease the interview process for the child and adolescent. Kay, Cree, Tisdall and Wallace (2003) advises researchers to be constantly alert to responses in order to respect any reluctance to answer questions that may be difficult or painful. It is important to be mindful that whilst participants may agree to participate in the research, they may be unwilling, shy or embarrassed which could affect their participation (Fargas Malet et al., 2010). Before the interview process, I engaged in "ice-breaker" conversations with participants, such as asking what the participant had done that day and asking them to tell me a little bit about themselves, such as who they live with, if they had any pets and what their hobbies were, which helped to settle any nerves and grasp the participant's communication style. Throughout the interview process, I also regularly "checked in" with the participants, by asking how they were feeling throughout the interview process, whether they were tired or if a question was difficult to answer, to ensure that they were feeling comfortable with the interview process itself and with the questions being asked.

2.7.2. Ethical considerations of conducting quantitative research with children and adolescents

Shaw, Brady and Davey (2011) specified guidelines when conducting quantitative research with children and adolescents. If children were under the age of 12 when completing questionnaires, it was advisable to do so with support, to ensure that individuals, particularly those with learning difficulties,

were not excluded or negatively impacted by the study. In my questionnaire study, children and adolescents were told that if they wished, they were allowed to have the support of parents to read the questions with them and explain any questions whilst they completed the questionnaires.

With web-based questionnaires it can be difficult to obtain parental consent as such platforms do not necessarily allow for consent forms to be signed. In order to work around this, an online platform that could enable participants and parents to 'sign' an online consent form was required. NHS ethical approval was sought and granted to upload the coping scale, and other validation scales on to the online survey platform Qualtrics (See Chapter 6). The functions of Qualtrics allowed me to upload the same information regarding consent as a hardcopy consent form and allowed for parents and participants to sign these online consent forms online using their mouse or their finger (if completing the study on their tablet or mobile phone), thus minimising the difficulties in obtaining informed consent when completing the study online. An additional benefit of this function was that children and adolescents could not access the questionnaires, and therefore could not complete the study if both parent and participant did not provide a signature, therefore minimising the ethical issue of consent if completing the study online.

In order to ensure confidentiality and provide participants with the right to withdraw, participants, generated their own participant code using the last two letters of their first name and the day of the month they were born. In case of duplicate codes being generated if more than one child had the same last two letters and date of birth, parents were also asked to generate a code using the first two letters of their first name and the day of the month they were born and were given my contact details in case their child wished to withdraw their data from the study. If wanting to withdraw from the study, participants were informed that they or their parent could contact me via email with their participant codes and request to withdraw from the study, and that no reason to withdraw would be necessary. My contact details were also provided in case they had any questions about the study, along with the website address and contact details of Allergy UK if participants or parents needed any advice about their FA.

2.8. Summary

This chapter has discussed the aims of the research, and the methodological approach for data collation and analysis for each of the empirical studies in this thesis. How each empirical study flows and fits within the overall thesis is shown in Figure 2.2.

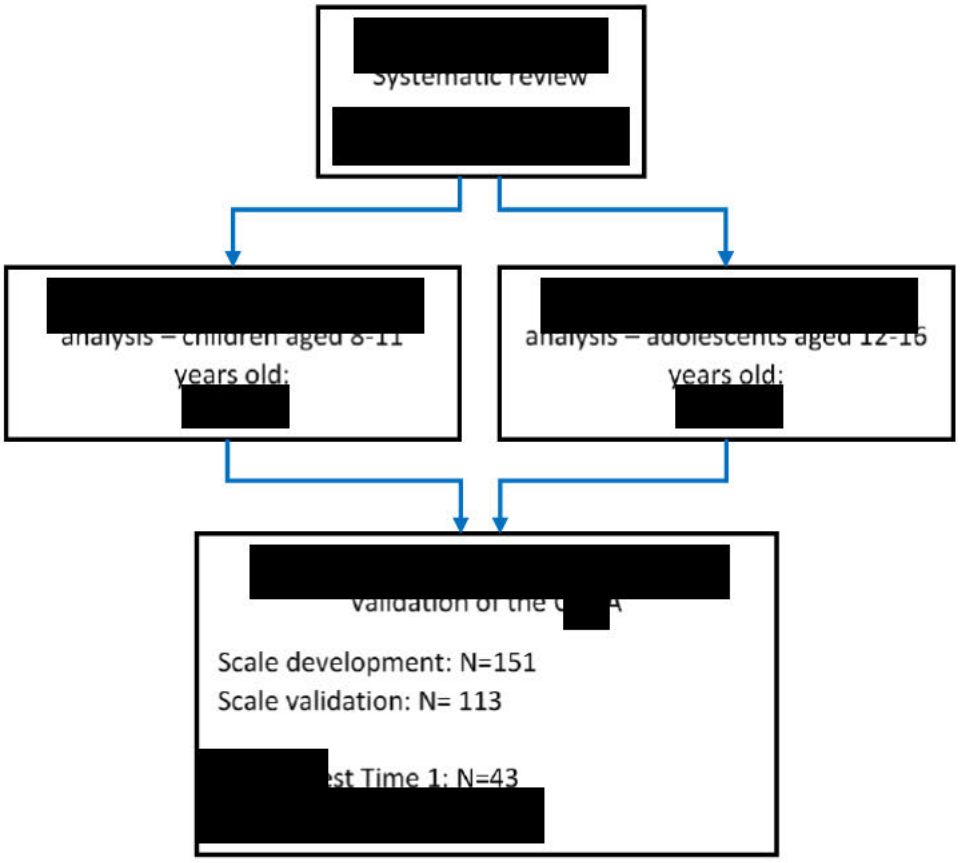

Figure 2.2: Flow chart of empirical studies

This chapter has also detailed the researcher's epistemological position of pragmatism and the use of mixed methodology in this thesis. The uses and application of qualitative and quantitative approaches of the empirical studies within the thesis were explained and how they fit with the aims of the research. Finally, this chapter highlighted the ethical considerations of research with children and adolescents, and how these issues were addressed.

CHAPTER 3 An examination of coping behaviours in children and adolescents with food allergy: a systematic review of qualitative and quantitative studies

3.1. Overview

In this chapter, a systematic review of qualitative and quantitative literature was conducted to synthesise and broaden our understanding of the types of coping behaviours used by children and adolescents with FA. The process of identifying, selecting and appraising the quality of the studies was systematic, using validated guidelines and tools to support the process and to limit subjectivity. A narrative approach, using thematic analysis (TA), was taken to present the data, synthesise and interpret the findings and emerging themes of fifteen studies that meet the inclusion criteria. Four themes were identified that reflected the types of coping strategies used by children and adolescents with FA. Though not without controversy rooted within its potential for bias and the philosophical tension between the constructivist, thoughtful analysis with the positivist "audit-driven culture", there is value in qualitative synthesis to broaden our understanding of the phenomenon studied, and create value and meaning (Bearman & Dawson, 2013).

3.2. Background

As highlighted in Chapter 1, literature on FA in children and adolescents has focused on the impact of FA on children and adolescent's such as QoL or psychological functioning. The qualitative methodology and the narrative that is drawn from these studies indicates the types of coping strategies children and adolescents use, such as carrying adrenaline auto-injectors (AAI), avoiding allergenic foods or using social-support. Existing studies have also identified several factors that appear to determine how children and adolescents cope with their FA. These include location for example home vs. restaurants; (Stjerna, 2015), the level of social support from family and friends (DunnGalvin et al., 2009); knowledge of FA including how to treat an allergic reaction (Gallagher et al., 2011); and age as children are more likely to seek support from parents compared to adolescents (DunnGalvin et al., 2009; Fenton, Elliot, Cicutto, Clarke, Harada et al., 2011).

More recently, DunnGalvin and colleagues (2018) conducted secondary analysis on data from interviews with 274 participants aged 6 – 29 years old from 5 different countries, to understand how FA impacts experiences, emotions and mediators of coping style. They postulated that early life experiences can be the foundation for later behaviour. Emotions attached to living with FA, such as fear or embarrassment, could also drive a search for 'normality' that could lead to the development or use of particular coping strategies. Despite these findings, in general very few studies have specifically focused on what types of coping strategies are used by this population.

Research into coping with chronic illness in children and adolescents has demonstrated that coping can be complex. Stressors can be unique to the condition concerned, for example, cancer-related stressors for children undergoing treatment are not necessarily relatable to general life stressors (Compas et al., 2012). Furthermore, studies have established that effective coping has been found to have favourable outcomes across a range of chronic conditions, such as a reduction in depressive symptomatology in adolescents with inflammatory bowel disease (Szigethy et al., 2004), and effective self-management for diabetic patients (Fisher, Thorpe, & DeVellis, 2007; Kent, Haas, Randal,Lin, Thorpe,et al., 2010, Grey, Boland, Davidson & Tamborlane. 2000). As effective coping can have favourable outcomes for those living with chronic conditions, it is important to identify how children and adolescents are coping with their FA in order to reduce the detrimental impact FA can have on health, QoL, psychological distress and mental well-being as identified by existing literature (King et al., 2009; Marklund, Wilde-Larsson, Ahlstedt & Nordström. 2007; Teufel, Biedermann, Rapps, Hausteiner, Henningsen et al., 2007).

Johnson and Woodgate (2017), conducted a meta-aggregation of the experiences of adolescents (aged 12 to 19) with food-induced anaphylaxis. The key findings of this review were that only a small body of qualitative research exists in the area of adolescent experience with food induced anaphylaxis and that adolescents with FA experience an identity shift and must find a balance in coping with burden and learn to negotiate risk in a world that can be beyond their control. Though this review described how adolescents coped with the burden of FA to an extent, coping was not the primary topic being investigated and so the findings of this review does not describe the types of coping strategies being used by adolescents, and the contexts with which they were identified. Additionally, this review did not include the perspectives and experiences of children below the age of 12 years old. Age is related to the types of coping strategies used, with the use of emotion-focused coping strategies, such as distraction, decreasing with age into adolescence (Hampel & Petermann, 2005). Furthermore, this review excluded studies using quantitative methodology which might have provided further insight and understanding into the way's children and adolescents cope, and the associations coping can have with outcomes such as QoL or psychological functioning.

In summary, whilst there is literature that explores the impact of FA on the lives of children and adolescents, few studies have specifically focussed on the coping strategies used by this population. To date, only one review has investigated the experiences of adolescents with FA that touch upon how adolescents cope. However, the findings do not describe the types of coping strategies used and exclude an age group where differences in the types of coping strategies used have been identified.

3.3. Aims and objectives

This systematic review aims to broaden knowledge and understanding of strategies used by children and adolescents to cope with FA. To provide a systematic description of the coping strategies identified, this review utilises the CBMC (Compas et al., 2001) to identify and categorise the coping strategies reported

by children and adolescents with FA in studies included in the review, and aims to address the following key questions:

1. What are the types of coping strategies used by children and adolescents to cope with FA?
2. What factors, if any, influence the use of coping strategies identified?
3. What are the barriers and facilitators, if any, to coping with FA in this population?

3.4. Methods

3.4.1. Developing the search strategy

I conducted an initial search of the Cochrane Database of Systematic Reviews Library and the Centre for Reviews and Dissemination and did not identify any existing systematic reviews that investigated coping in children and adolescents with FA. Following this, I conducted an initial scoping search on Web of Science using the terms 'coping' AND 'food allerg*' AND 'child*' OR 'teenagers' OR 'adolescents'. A number of studies using both qualitative and quantitative research methods with participants of the age range of my thesis (8-16 years old) also included participants aged up to nineteen years old. Although outside of the age range of my thesis, to avoid excluding any studies that would be relevant to the aims of the review, it was decided that qualitative, quantitative and mixed-methods studies with participants aged up to nineteen years old would be included in the systematic review.

As qualitative, quantitative and mixed-methods studies were to be included in the review, the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool for qualitative evidence synthesis developed by Cooke, Smith and Booth (2012) was used to aid the development of the inclusion and exclusion criteria and the search terms. This tool was chosen over the PICO method (Population, Intervention, Comparison, Outcome), which has been argued to be more suited to quantitative systematic reviews than qualitative evidence synthesis (O'Connor, Green & Higgins, 2008;Cooke et al., 2012). The nature of qualitative research has been argued to raise a challenge for the synthesis of results and evaluation (Atkins, Lewin, Smith, Engel, Fretheim et al., 2008; Barbour & Barbour, 2003). However, qualitative studies can provide a nuanced picture of a complex phenomena (DunnGalvin et al., 2018). Including qualitative research can enhance systematic reviews (Higgins & Green, 2011) and help to understand the "what, how and why" of the research question (Sheldon, 2005).

To be inclusive of all conditions where food causes symptoms, and the published nomenclature of FA by Johansson et al. (2004), papers using or including participants diagnosed with the following terms were included in the search strategy: 'food allergy' (FA) to refer to immunological reactions to food; 'food intolerance' (FI) to refer to non-immunological reactions to food; 'food hypersensitivity' (FH) to refer to FA or intolerances.

3.4.2. Inclusion and exclusion criteria

The inclusion and exclusion criteria are outlined in Table 3.1.

Table 3.1: Inclusion and exclusion criteria

Category	Inclusion criteria	Exclusion criteria
Sample	• Children and adolescents aged 6-19 • Diagnosis of FA, FI, FH	• Studies that include participants outside of the age range of 6 -19 years old but data from 6-19 years olds cannot be separated from the data. • Parents of children with FA • Adults with FA • Medical/nursing staff • School staff
Phenomenon of interest	• Behaviours or strategies indicative of coping with FA	• Behaviours or strategies that are not indicative of coping, e.g. medical/biological results, results of QoL, anxiety and depression with no data associated with coping strategies
Design	• All research designs for qualitative, quantitative and mixed-methods e.g. interview, focus group, questionnaire	• No study design will be excluded
Evaluation	• Outcomes related to coping behaviours or coping strategies	• Studies where outcomes are unrelated to coping e.g. medical/biological results, QoL, psychological functioning with no data associated with coping strategies
Research type	• Qualitative, quantitative and mixed methods	• Reviews/book chapters/abstracts/letters/commentaries that contain no primary data

3.4.3. Sample

Studies sampling children and adolescents aged 6-19 years old with a diagnosis of FA, FI or FH, either through self-report or by a clinical diagnosis were included in the review. Where articles sampled participants outside of the age-range, only those that had data relating to participants aged 6-19 that were reported separately or could be separated within the results were included in the review. Although as mentioned in Chapter 2, the lower age limit of 8 years was chosen for this thesis, for the purpose of this systematic review and to avoid omitting any studies that might be relevant to the research question review, I decided to extend the lower age limit to 6 years old. The adolescent age range was defined as those over the age of 12 years old (Jawkorska and MacQueen, 2015), and the age range of children to 11 years old and younger.

3.4.4. Phenomenon of interest

The main phenomenon of interest was coping strategies in children and adolescents with FA. However, due to a lack of literature that has focused on coping strategies in this population, behaviours demonstrated by children and adolescents with FA which were indicative of a coping strategy, as guided by the CBMC (Compas et al., 2001) were included in the review.

3.4.5. Design

Based on the initial scoping search conducted which identified studies using qualitative and/or quantitative methodology using interviews, focus groups or questionnaires, studies of any design were included in the review.

3.4.6. Evaluation

Outcomes related to measurement of coping strategies using validated measures of coping were included in the review. Where this would be unavailable, such as in qualitative studies, the three constructs of the CMBC: primary-control coping, secondary-control coping and disengagement coping, were used to aid the identification and categorisation of any strategies or behaviours that were indicative of coping.

3.4.7. Research type

Based on the initial scoping search, three research types were included in the search: quantitative, qualitative and mixed methods. Reviews, abstracts, letters and commentaries that did not include primary data were excluded.

3.4.8. Definition of coping

Coping was defined as "conscious volitional efforts to regulate emotion, cognition, behaviour, physiology, and the environment in response to stressful events or circumstances" (Compas et al., 2001. Pg. 89). The three components of the CBMC were used to identify coping behaviours: primary-control coping, secondary-control coping, and disengagement coping (Table 3.2).

Table 3.2: Components of the Control-Based Model of Coping (Compas et al. 2001, 2005, 2012)

Component	Description
Primary-control coping	Efforts to change a stressor (e.g. problem solving) or one's emotional reactions to a stressor (e.g. emotional expression, talking to someone).
Secondary-control coping	Efforts to adapt oneself to a stressor by strategies such as cognitive reappraisal, positive thinking, acceptance, and distraction.
Disengagement coping	Efforts to orient away from a stressor or one's reactions to a stressor (e.g. avoidance, denial).

3.4.9. Year of publication

The search for literature was limited to articles published from January 2000 to September 2018 to ensure that research was relevant to the current management of FA in children and adolescents.

3.4.10. Identification of studies

The following databases were systematically searched: PubMed, SCOPUS, and Web of Science. Papers were restricted to those in the English language.

3.4.11. Additional search strategies

References within included papers were checked to ensure no relevant papers were being missed.

3.4.12. Search terms

Search terms were developed using the SPIDER tool in consultation with an information specialist at Aston University and with the supervisory team.

1. coping AND food allerg* AND children
2. coping AND food allerg* AND teenager OR adolescent
3. manag* AND food allerg* AND children OR adolescent
4. ((risk AND behavio* NEAR/3 food allerg*)) OR ((risk-behavio* NEAR/3 food allerg*))
5. risk AND behavio* AND children or adolescent AND food allerg*
6. ((risk AND behavio* AND children NEAR/3 food allerg*)) OR ((risk AND behavio* AND teenager NEAR/3 food allerg*))
7. adherence AND food allerg* AND children OR teenager
8. autoinjector AND children OR teenager AND food allerg*
9. autoinjector AND children OR teenager NEAR/3 food allerg*

The words ‘food hypersensitivit*’ ‘food intolerance’, ‘peanut allerg*’, ‘nut allerg*’, ‘milk allerg*’ and ‘egg allerg*’ were also searched for by replacing the term ‘food allerg*’ in the search strings above, e.g. ‘coping AND peanut allerg*AND teenagers’. These foods were used within the search strings, as these are the common types of FA in the United Kingdom (Venter et al., 2006).

3.5. Data collection and analysis

3.5.1. Study screening and selection

I screened all titles and abstracts of papers retrieved using the search strings outlined above. Endnote was used to manage the references and remove any duplicates. Following the removal of duplicates, papers were assessed against the inclusion/exclusion criteria at title and abstract level. Papers that were unclear or raised questions regarding inclusion were not excluded at this stage and were discussed with the supervisory team regarding eligibility for inclusion. The full texts of potentially eligible papers were obtained and assessed against the inclusion/exclusion criteria. Following the guidelines of the Cochrane

Handbook for Systematic Reviews (Higgins & Green, 2011), the principal and associate supervisor each independently assessed 10% of the retained studies for eligibility against the inclusion/exclusion criteria, with both supervisors receiving different sets of papers to review.

3.5.2. Data extraction method

A data extraction form was used to collect the required information. The form was adapted from the Cochrane Collaboration, and included components of the SPIDER tool which formed the inclusion and exclusion criteria (Appendix 2). Extracted data included: authors, aims of the study, sample, study setting, data collection method, data analysis method, and summary of findings.

3.5.3. Quality assessment

Studies were appraised using the Mixed Methods Appraisal Tool (MMAT) (Pluye, Robert, Cargo, Bartlett, O'Cathain et al., 2011), a critical appraisal tool designed for use in systematic reviews that include quantitative, qualitative and mixed methods studies. The MMAT has been established to be an effective tool for such reviews (Pace, Pluye, Bartlett, Macaulay, Salsberg et al., 2012; Souto, Khanassov, Pluye, Hong, Bush et al., 2014). The MMAT comprises five categories: qualitative; quantitative randomised controlled (trials); quantitative non-randomised; quantitative descriptive and mixed method. Each category has associated methodological quality criteria which studies are appraised against. These result in a quality score from 0%, 25%, 50%, 75% and 100% (Appendix 3). The supervisory team also undertook quality ratings of the studies using the MMAT

3.5.4. Data synthesis and analysis of results

A narrative synthesis approach was adopted by using words and text to interpret and summarise the findings, following the guidance by Popay et al. (2006). Narrative synthesis is an approach that relies primarily on words and text to summarise and explain the findings of the synthesis. It adopts a textual approach to the process of the synthesis to "tell the story of the findings from the included studies" (p.5) and can be used in systematic reviews focusing on a wide range of questions, and not just those "relating to the effectiveness of a particular intervention" (p.5).

TA was used to identify commonalities within the data from the qualitative and quantitative studies, and to generate themes that explore coping in children and adolescents with FA. TA was chosen as the aim of the analysis of the review was to summarise the qualitative data reported by authors, rather than developing theory or exploring lived experience where methods such as IPA may have been more suitable. Furthermore, TA is a common technique in the analysis of qualitative data in primary research, and for the purpose of a narrative synthesis, it can be used to identify the main, recurrent and/or most important themes or concepts across multiple studies (Popay et al. 2006). This method of qualitative analysis has also been used in other systematic reviews where qualitative and quantitative studies have been included (see Belanger, Rodriguez & Groleau, 2011 and Darlow, Fullen, Dean, Hurley, Baxter et

al., 2012). In quantitative studies, written analysis or explanations of the data were coded and analysed in the same way as qualitative data.

Results of the included studies were coded inductively line by line with coping behaviours, for example, "using AAI", "avoiding foods". Where available, quotes within the studies were also coded in the same way or identified as a supporting statement to the coping strategy identified. Similar codes, or codes with a common basis, were grouped together. For example, "using AAI" or "leaving AAI at home" were grouped under the main code "AAI". A deductive approach was then used, and results were again coded line by line, applying the constructs of the CBMC to the text (see Appendix 4) for an example of inductive and deductive coding). To understand the association between the inductive and deductive codes, abductive reasoning was adopted during analysis to provide an explanation between data and theory by drawing the two processes of inductive and deductive analysis together (Hiles, 2014). This method of abductive reasoning involved a recurring process of mapping the inductive main codes and sub-codes against the deductive codes of the components of the CBMC. This resulted in a thematic map based on the process of abductive reasoning that explored how children and adolescents coped with their FA and demonstrated the complexity of coping behaviours (see Appendix 5 for an example of the mapping process).

3.5.5. Validity and reliability

Reliability cannot always be replicated in qualitative syntheses due to the interpretative approach used to review literature (Dixon-Woods, Cavers, Agarwal, Annandale, Arthur et al., 2006). Attempts at transparency were made by presenting summary tables of the included and excluded studies. Triangulation and reflexive analysis were employed through regular dialogue between myself and my supervisory team during the finalising of included papers, synthesis of data and identification of coping strategies, and the development of themes.

3.6. Results

3.6.1. Literature search

Searches across the electronic bibliographic databases outlined in section 3.4.10 were conducted on 1st September 2018 and generated 7687 records, a large proportion of which were biological studies of FA. After the removal of duplicates (n=3996), I screened 3691 records against the inclusion and exclusion criteria at title and abstract level. This resulted in the removal of 3584 records, and the retrieval of 115 full-text articles (see Figure 3.1).

3.6.2. Description of excluded studies

A table of excluded studies is presented in Appendix 6. There were five reasons for excluding studies. Forty-five studies were excluded as outcomes were unrelated to coping, such as describing quality of life, anxiety or depression. This included a pilot study of a coping toolkit which investigated ease of use

and feasibility, but did not expand on the coping strategies used by children and adolescents. Twenty-six papers were excluded because they were review articles, papers or letters to editors that did not report primary data. This included the meta-aggregation of the qualitative experiences of adolescents (aged 12 to 19) with food-induced anaphylaxis by Johnson and Woodgate (2017) and a paper by DunnGalvin et al. (2018) that specifically focussed on understanding coping strategies in children and adults aged 6-23 years old through analysis of secondary data. Twenty-two studies were excluded as participants were not children or adolescents. Sevens studies were excluded as participants were children or adolescents outside of the age range, or the data of children and adolescents within the age range of the inclusion criteria could not be identified within the data.

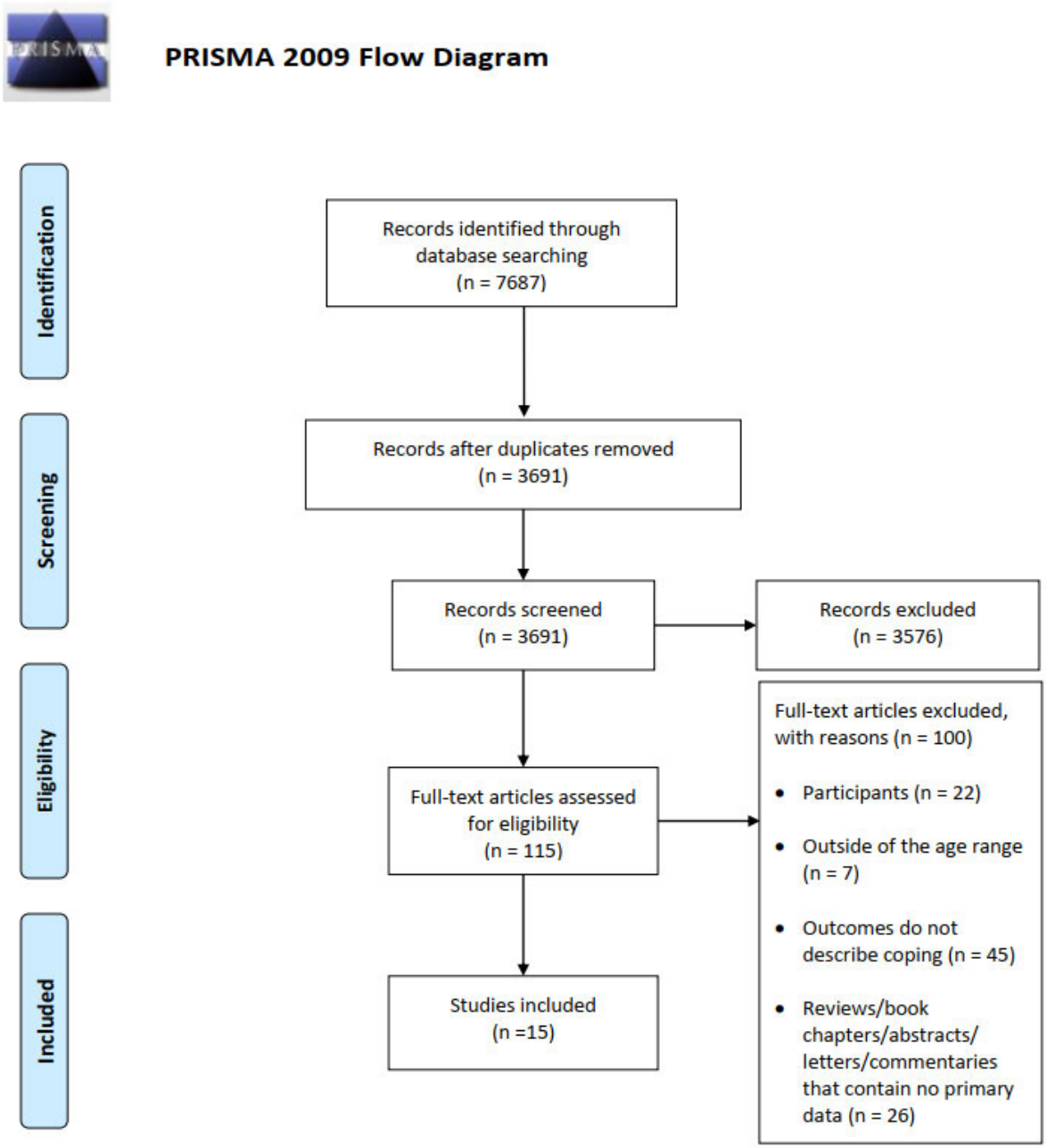

Figure 3.1: PRISMA flow diagram (Moher, Liberati., Tetzlaff, Altmam & The PRISMA Group, 2009).

3.6.3. Description of included studies

Fifteen studies were included in the review. Across the fifteen studies, data was collected from 503 participants ranging from 6 to 19 years old. The studies were published between 2007 and 2017, conducted in the UK (k=8), Sweden (k=2), Canada (k=1), Denmark (k=1), Ireland (k=1), the Netherlands (k=1), and United States of America (k=1).

Twelve studies adopted a qualitative methodology, using semi-structured interviews (k=9), focus groups (k=1) or both focus groups and interviews (k=2) to collect data. Two studies (Gallagher et al., 2011; Macadam et al., 2012) specifically explored the topic of adrenaline auto-injectors (AAI), one study explored the strategies for living with risk of anaphylaxis (Gallagher, Worth, Cunningham & Sheikh, 2012), and two studies used the terminology of food hypersensitivity (FH) instead of FA study (Marklund, Wilde-Larsson, Ahlstedt & Nordstrom , 2007; Mackenzie, Roberts, Van Laar, & Dean, 2009). Three studies adopted a quantitative methodology, using self-report measures to obtain data from psychometric measures such as the "How I coped under pressure" scale, the "Child PTSD Symptom scale" (Weiss & Marsac, 2016), and an adaptation of a questionnaire using constructs of the Health Belief Model (Jones et al., 2015) the Food Allergy Quality of Life Questionnaire (teenage form), Food Allergy Independent Measure, a measure looking at burden of treatment (not specified) and the Brief Illness Perception Questionnaire (Saleh-Langenberg, Flokstra-de Blok, Goossens, Kemna, van der Velde et al., 2016). See Table 3.3 for characteristics of included studies, including the themes that the studies are attributed to in the systematic review.

3.6.4. Quality of included studies

The quality of the included studies was mixed, although no study achieved a score below 50%. The principal and associate supervisors and I separately appraised the included studies using the MMAT. Following our individual appraisals, we discussed our scorings together and where we had any considerable differences. Agreement on scores that differed between us were reached through discussion.

Qualitative studies were assessed against the qualitative criteria. Only six studies (Fenton et al., 2011; Gallagher et al., 2012; Macadam et al. 2012., Marklund et al., 2007., Saleh-Langenberg et al. 2016, and Weiss and Marsac, 2016) scored 100%, and the scores of the remaining qualitative studies ranged from 50% and 75%. Eight studies (Akeson, Worth & Sheikh. 2007., DunnGalvin et al., 2009; Gallagher et al., 2011; Mackenzie et al., 2010; Monks et al., 2010; Sommer, MacKenzie, Venter & Dean. 2014; Stengsaard, Bindslev-Jensen & Nielsen, 2017 & Stjerna, 2015) did not provide an explanation for criteria 3, whether *"appropriate consideration had been given to how findings relate to the context e.g. the setting in which data were collected*". For one study (Stjerna, 2015) it was difficult to establish if it met criteria 4 *"if consideration was given to how findings related to researchers' influence, e.g., through their interactions with participants"* as nothing was reported for this. Five studies (Fenton et al., 2011;

Gallagher et al. 2011; Gallagher et al., 2012; Sommer et al., 2014; Stensgaard et al., 2017.) did not explicitly state if they had participants decline to participate, or if they did, they did not state why participants declined to participate.

The three quantitative studies were appraised against the quantitative descriptive criteria, with scores ranging from 75% to 100%. Only two of these studies (Saleh-Langenberg et al., 2016, and Weiss & Marsac, 2016) scored 100%. One study (Jones et al., 2015), had a low response rate of 32%, against the MMAT recommendation of a response rate of at least 60% (See Table 3.3 for MMAT scores of each included study).

3.6.5. Thematic analysis

Thematic analysis of study results generated four themes that explained the different coping strategies used by children and adolescents with FA, and the types of barriers or facilitators that influence the use of certain methods of coping. The four themes were: 'coping with food allergy: navigating different locations; 'coping with the emotional burden of food allergy; 'seeking support from others' and 'carrying and using adrenaline-autoinjectors (AAI)'. The strategies used by children and adolescents identified in the data were categorised against the components of the CBMC as either primary-control, secondary-control or disengagement coping (Compas et al., 2012). If provided, quotes from included articles are presented throughout the results. Where possible, the name and age of the participant from the relevant study is also included.

3.6.6. Theme 1: Coping with food allergy: navigating different locations

The influence of location on coping strategies used by children and adolescents was identified in ten papers (Akeson et al., 2007; DunnGalvin et al., 2009; Fenton et al., 2011; Gallagher et al., 2012; Macadam et al., 2012; Mackenzie et al., 2009; Monks et al., 2010; Marklund et al., 2007; Sommer et al., 2014; Stjerna, 2015). Children and adolescents reported using strategies indicative of primary-control and disengagement coping. The type of strategy used depended on the location children and adolescents were asked about. Three locations that affected how children and adolescents coped were identified across the ten papers: restaurants, school and holiday destinations.

For example, DunnGalvin et al. (2009) found that children and adolescents proposed a dichotomy between "safe" and "risky" places. Home was the most common example of a "safe" environment, whilst in contrast, Stjerna (2015) and Gallagher et al. (2012) identified that children and adolescents perceived public places, such as restaurants, as high-risk and presented significant challenges for FA management.

Table 3.3: Characteristics of included studies

Authors	Aims	Participants	Country	Data Collection	Data analysis	Summary of findings	Themes	MMAT rating
Akeson et al.,(2007)	To explore the psychosocial impact of living with anaphylaxis on adolescents and their parents; their management of the condition; and perceptions of health care provision	Age: 13-15 Total: n=7	UK	Individual interviews.	Framework approach.	Main themes identified; Mostly respect for and confidence in managing the allergy, but less knowledgeable than parents; Allergy perceived as 'not a big deal'; Lower and narrower perception of risk in comparison with parents; Inconsistency in carrying adrenaline due to practical and psychosocial obstacles; Mistrust in food labelling.	1, 2, 3, 4	(75%)
DunnGalvin et al., (2009)	To provide a framework to explain onset, development and maintenance of FA-related cognitions, emotions and behaviour.	Age: 6-15 Total: n=62	Ireland	Focus groups.	Thematic analysis.	Six themes: 1) meanings of food, 2) sense of identity, 3) peer relationships, 4) risk and safety, 5) autonomy, control and self-efficacy, 6) active and interactive strategies to cope with FA.	1, 2, 3	(75%)
Fenton et al., ,2011)	To explore the perception and experiences of anaphylaxis.	Age: 7-17 Total: n=20	Canada	Qualitative interviews and illustrations.	Thematic analysis.	Five themes: 1) social and environmental barriers to safety, 2) coping strategies, 3) emotional burden of responsibility, 4) balance of responsibility, 5) redefining normal.	1, 2, 3	(100%)
Gallagher et al., (2011)	To gain knowledge of adolescents' attitudes towards and experience of auto-injectors (AI) to inform improvements in patient education.	Age: 13-19 Total: n= 26	UK	Semi-structured individual interviews.	Thematic analysis.	Six themes: 1) Training in AI technique, 2) carrying and storing AI, 3) identifying an anaphylactic reaction, 4) knowing when to use an AI, 5) Administration technique, 6) potential intervention to improve AI use among adolescents.	4	(75%)

Table 3.3 (continued)

Authors	Aims	Participants	Country	Data Collection	Data analysis	Summary of findings	Themes	MMAT rating
Gallagher et al., (2012)	Explore experiences of adolescents living with risk of anaphylaxis; understand parent's perspectives and how care might be improved.	Age: 13-19 Total: n=26	UK	Semi-structured individual interviews.	Thematic analysis.	Six themes: 1) experience of anaphylaxis, 2) managing allergies and preventing further reactions, 3) eating away from home, 4) risk and "may contain" labels, 5) support from healthcare professionals, 6) transition from parental to self-management.	1, 3, 4	(100%)
Jones et al., (2015)	Using the health belief model to explore the relationship between food allergic adolescents' health beliefs, demographic, structural and social psychological factors with adherence to self-care behaviours, including allergen avoidance and carrying emergency medication.	Age 13-19 Total: n=188	UK	Self-report survey measures.	Multivariate analyses. Stepwise logistic regression. Nonparametric bivariate associations.	Full adherence was reported by 16% of participants. Multivariate analysis indicated that adherence was more likely to be reported if the adolescents belonged to a support group (OR = 2.54, (1.04, 6.20) 95% CI),, had an anaphylaxis management plan (OR = 3.22, (1.18, 8.81) 95% CI), perceived their FA to be more severe (OR = 1.24, (1.01, 1.52) 95% CI) and perceived fewer barriers to disease management (OR = 0.87, (0.79, 0.96) 95% CI).	3, 4	(75%)
Macadam et al., (2012)	Investigating barriers to auto-injector (AI) carriage in teenagers.	Age: 12-18 Total: n=16	UK	Semi-structured individual interviews.	Thematic analysis.	Six themes: 1) role of circumstances, 2) type of allergy, 3) attitudes about the device, 4) responsibility and attitudes of others, 5) feelings and attitudes of allergic teenagers to AI.	1, 2, 3, 4	(100%)

Table 3.3 (continued)

Authors	Aims	Participants	Country	Data Collection	Data analysis	Summary of findings	Themes	MMAT rating
Mackenzie et al., (2009)	To describe the lived experiences of teenagers living in the UK with food hypersensitivity.	Age: 13-18 Total: n=21	UK	Semi-structured individual interviews.	Phenomeno-logical analysis.	Two patterns identified: 1) those living with FHS since infancy, 2) those who develop FHS later. Four themes: 1) Living with FHS as a way of life, 2) Living with FHS as experiencing and coping with burden, 3) Alleviation/exacerbation of the burden of living with FHS, 4) managing acceptable risk.	1, 2	(75%)
Marklund et al., (2007)	Explain adolescent's experiences of being food hypersensitive (FHS).	Age: 14-17 Total: n=17	Sweden	Three focus group interviews, and six individual interviews.	Thematic analysis.	Five themes with subcategories: 1) perceiving oneself as particular, 2) feeling constrained, 3) experiencing others' ignorance, 4) keeping control, 5) feeling its ok. One main theme: striving to normalise FHS.	1, 2	(100%)
Monks et al., (2010)	To understand that challenges that food allergic teenagers have and how they cope.	Age: 11-18 Total: n=18	UK	Semi-structured individual interviews.	Thematic analysis.	Four themes: 1) Allergen avoidance, 2) self-injectable adrenaline, 3) Treatment of reactions, 4) Education about FA.	1, 2, 3, 4	(75%)
Saleh-Langenberg et al., (2016)	To determine the burden of treatment (BoT) of an epinephrine auto-injector (EAI) and examine the relationship between compliance and burden.	Age 13-17	The Netherlands	Self-report survey measures.	Spearman's correlations. Fisher's exact test. Mann-Whitney U-test.	Low BoT associated with being positive about EAI. BoT was higher in food-allergic adolescents prescribed an EAI who reported not carrying the EAI at all times. The BoT of an EAI is not associated with HRQL. No significant association between the BoT and the number of FA ($p = 0.52$).	2, 4	(100%)

Table 3.3 (continued)

Authors	Aims	Participants	Country	Data Collection	Data analysis	Summary of findings	Themes	MMAT rating
Sommer et al., (2014)	To understand how teenagers with food allergies make food choice decisions and how this differs to non-food allergic teenagers.	Age: 12-18 Total: teenagers with FA, n=7	UK	Focus groups and individual interviews.	Thematic analysis.	Six themes: 1) variety and enjoyment of food as learning process, 2) body awareness, feelings and temptations of foods, 3) parental control vs convenience, 4) eating as a social experience, 5) routine, traditions and environment, 6) knowledge shapes understanding of food.	1, 3	(75%)
Stensgaard et al., (2017)	To explore and better understand the impact that peanut allergy can have on family experiences in everyday life through interviews with individual family members	Age: 15-16	Denmark	Semi-structured individual interviews.	Phenomeno-logical-hermeneutic approach.	Three themes: 1) the nuclear family - safety and understanding. 2) When the nuclear family is challenged. 3) The importance of having a social life.	3, 4	(75%)
Stjerna (2015)	To explore young people's management of FA risk and their agency in relation to food	Age: 11-17 Total: n=11	Sweden	Semi-structured individual interviews	Thematic analysis.	Two themes: 1) Management of health risks, 2) management of social risks in different places.	1	(50%)
Weiss & Marsac (2016)	Describe coping, prevalence for post-traumatic stress symptoms, and the association between the two.	Age: 7 -13 Total: n=25	USA	Self-report survey measures	Descriptive statistics. Independent-samples t tests. Pearson bivariate correlations.	Each type of coping used with similar frequency: cognitive restructuring (CR) (mean [SD], 2.6 [0.7]), social support (SS) (mean [SD], 2.6 [0.9]), avoidance (mean [SD], 2.7 [0.5]). Effect sizes suggested possible differences. The number of FA was not significantly related to coping (r=0.06-0.24, P > .50)	2, 3	(100%)

Dining in restaurants was described as "unpredictable" and could cause considerable stress due to a lack of awareness among restaurant staff around the severity of FA and the uncertainty around safety (DunnGalvin et al., 2009; Stjerna, 2015). Alva's quote below illustrates some of the challenges to coping with risk when dining out in public, and the uncertainty around her safety affected whether Alva would feel comfortable eating.

> *Alva: "If those who prepare food in different places don't know what they're doing, then it's really risky, and I wonder whether I should eat that sandwich or not." (Stjerna, 2015)*

Stjerna (2015) found that adolescents adjusted their approach to allergen avoidance according to the location they were in, and many reported having to be vigilant and responsible for making their own risk assessment of where and what food they could eat. Some adolescents were not prepared to take any risks with their FA (Mackenzie et al., 2009) and coped by carrying their AAI with them at all times (Gallagher et al., 2012). In extreme circumstances, some adopted disengagement coping strategies by refraining from eating out at all in public (Marklund et al., 2007). In some cases, the more familiar a location, the more risks an adolescent would take such as with the foods they would eat (Monks et al., 2010).

Studies by Gallagher et al. (2012) and Sommer et al. (2014) found that adolescents (ranging from aged 12 to 19 years old), used behaviours indicative of primary-control coping in restaurants, such as carrying an AAI, avoiding foods that may contain an allergen, or making enquiries about food content (Gallagher et al., 2011; Sommer et al., 2014). Social support was also identified as parents were sometimes relied upon to ask about ingredients in restaurants (Fenton et al., 2011). Some adolescents also coped by always eating the same safe products or going to the same restaurants (Stjerna 2015). Behaviours indicative of disengagement coping were also identified. Some adolescents would avoid eating out in restaurants due to the difficulty in risk management (Gallagher et al., 2012). Others would cope by minimising the seriousness of their FA. This would be done by downplaying its severity and taking calculated risks with their health, such as not carrying their AAI or eating potentially allergenic foods, particularly those that have not caused serious reactions so far or if an Accident and Emergency department was known to be nearby (Akeson et al., 2007; Mackenzie et al., 2009; Sommer et al., 2014).

> *A5: "It's just because I don't really know. Because I'd never really needed it, so I'd never got used to carry it. I'd never been used to carry it, so I don't remember to pick it up all the time. It's in my room but I don't take it because I do not need it. I don't need it. Because I wouldn't be eating nuts anyway." (Akeson et al., 2007)*

There was limited data for children under the age of 12 years old that related to dining in public, however, DunnGalvin et al. (2009) found that younger children had more confidence in social situations where risk may be higher as they relied more on their parents. For example, parents would inform others of their child's FA (DunnGalvin et al., 2009), an example of primary control coping in that environment.

Schools were viewed as unstructured and unsafe, particularly by adolescents as they had more choice with where they ate, who they socialised with and where lunch and snacks were obtained from if not supplied by parents (Fenton et al., 2011; Stjerna 2015). Some children and adolescents utilised primary control coping strategies to cope with their FA at school, such as asking friends to be careful with their food or enquiring about food content. (DunnGalvin et al., 2009.) Most adolescents coped with their FA in school by taking their AAI with them (Macadam et al., 2012). But for young children, social support was a key coping strategy at school, and for many, coping with their FA at school involved a greater dependence on parents to inform staff at school of their FA (Fenton et al., 2011).

> *"My mom usually goes in ahead of me and clarifies all that, so every once in a while, I will get a question about that from teachers or something. Well (my mom) just kind of like they take care of the situation, way before I even have to get involved." (Fenton et al., 2011)*

Macadem et al. (2012) identified behaviours in adolescents that were indicative of disengagement coping if they felt that school carried substantial risk to them, for example, by eating separately from their friends. However, disengagement coping could also involve not carrying an AAI if there were factors that adolescents felt negated the need to carry one for safety, such as having a packed lunch or feeling in control of their FA in what they perceived as a predictable or controllable environment (Macadam et al., 2012):

> *P11 (14 yrs): "We're meant to carry them [EpiPens] around school but I don't. I don't think there's much point…because I have a packed lunch…So I don't eat anything that I know might have a nut in." (Mackenzie et al., 2010)*

Similar to schools, foreign travel and holidays were seen as risky places and presented their own set of challenges to coping with FA due to the uncertainty of the content of foreign food, the language barrier and higher demands of care required, as Laura's quote below illustrates (Sommer et al., 2014).

> *Laura (15 yrs): "Um, I'm much more nervous about eating out when I'm on holiday because like it's a different language and I don't really know how to, and I don't know how to ask, um, whether something has nuts in it, so normally I'd just kind of eat stuff that seems like very safe." (Sommer et al., 2014)*

Due to the increased risk, most adolescents would take their AAI with them on holiday (Macadam et al., 2012). However, disengagement coping strategies were also identified in these contexts, such as restriction and avoidance with regards to what food was eaten, or in extreme cases, whether they would holiday at all (Gallagher et al., 2012).

Whilst there was an understanding of "avoidance" as the main form of allergy management in any type of location, this was highlighted as a process that was not straightforward. There was a view that food labelling was not always clear and a belief that 'may contain' labels were overused rather than indicators of genuine risk (Mackenzie et al., 2010). Despite reading food labels and assessing the food as safe to eat, some adolescents still experienced an allergic reaction (Gallagher et al., 2011). Many felt that being

given more detailed information and education on food avoidance would be useful, including labelling practices, in order to cope with their FA (Monks et al., 2010).

Overall, behaviours indicative of primary-control and disengagement coping strategies to cope with FA in different locations were identified in both children and adolescents. Where children and adolescents were and their perception of risk in that location, could influence the choice of coping strategy used. Children and adolescent demonstrated the use of primary control coping strategies in high-risk locations out of the home that would minimise or alleviate FA risk such as that of carrying their AAI, avoiding allergens, reading food labels or using social support. However, disengagement coping strategies such as avoiding certain locations and eating separately from friends were identified when children and adolescents felt the risk to their health was too great. It appeared that high-risk locations could also be a barrier to adaptive coping, particularly if children and adolescents felt that the best way for them to cope was through avoidance and restriction in their interaction with others.

3.6.7. Theme 2: Coping with the emotional burden of food allergy

Nine studies referred to coping with the emotional burden of FA, and coping strategies within this theme consisted of using primary-control, secondary-control and disengagement strategies in both children and adolescents (Akeson et al., 2007; DunnGalvin et al., 2009; Fenton et al., 2011; Macadam et al., 2012; Mackenzie et al., 2009; Marklund et al., 2007; Monks et al., 2010; Saleh-Langenberg et al.,2016; and Weiss & Marsac, 2016).

Being allergic to food had negative psychological and emotional consequences for children and adolescents (Marklund et al., 2007; Mackenzie et al., 2009; Weiss & Marsac, 2016). Being allergic to food caused them to describe feelings of sadness, annoyance and fear of their FA, or feeling overburdened (Fenton et al., 2011; Mackenzie et al., 2009; Saleh-Langenberg et al., 2016). DunnGalvin et al. (2009) found that discussing food could generate anxiety and distress in children as it was associated with allergic reactions and hospital attendance.

Behaviours indicative of primary control coping such as vigilance, maintaining cleanliness and social support were identified in children and adolescents, particularly following an allergic reaction. Increased vigilance meant being keenly aware of the presence of foods that could cause a reaction, and strictly avoiding them. However, for some adolescents, increased vigilance could be a result of the fear of an allergic reaction happening to them again, as described by a participant in the study by Marklund et al. (2007).

> *"Now, I don't dare to eat anything with fish or tomato because I'm scared it might happen again." (Marklund et al., 2007)*

Fenton et al. (2011) found that adolescents who felt helpless, disempowered and had feelings of being overburdened emotionally, were accompanied by responses and strategies that were overcompensating and consumed energy and attention on a daily basis, such as obsessive hand washing.

"Well it used to like kind of not be such a big deal, like I was like anyone else, because I wouldn't wash my hands before, and now it has gone to like a lot worse, where I am washing my hands all the time and stuff." (Fenton et al., 2011)

In a quantitative study, Weiss and Marsac (2016) found that children who had an anaphylactic reaction could have higher post-traumatic stress symptoms (PTSS), than children who had not experienced such a reaction. Children with significant PTSS were found to use support-seeking strategies, though the study did not provide further explanation on the source of this support.

DunnGalvin et al. (2009) identified that children and adolescents with high levels of anxiety and low levels of self-efficacy in managing their FA would use avoidant strategies. Two strands of avoidant coping were identified; those which deal with risk/emotions (e.g. anxiety), and those which manage identity. Strategies to manage anxiety would involve avoiding social situations where food would be involved, whilst strategies to manage identity would include avoiding disclosing their FA to other people such as friends. These strategies could be indicative of disengagement coping.

"I prefer to go to parties where there is no food." (DunnGalvin et al.,2009)

"In my new school, nobody knows except the teachers...it's better that way." (DunnGalvin et al.,2009)

DunnGalvin et al. (2009) also identified that children and adolescents with low expressed levels of anxiety, or had experienced bullying due to their FA, used minimisation strategies (also indicative of disengagement coping) such as cognitive minimisation, rejection of FA identity and taking part in 'risky' actions with their food. Children and adolescents who used minimisation strategies were found to take risks by eating potentially dangerous foods, or they would downplay the importance of carrying their AAI and forget it on purpose.

"Sometimes I 'forget' my pen on purpose." (DunnGalvin et al., 2009)

Some adolescents described feeling frustrated and fed up with having to check if food was safe for consumption and carrying their medication, and described these tasks as things that made them 'different' from their friends (Akeson et al., 2007).

A4: "It can be quite annoying because sometime when you go out and meet people and you have to show them, and they ask lots of questions about it and stuff…what's it for and what I can and can't eat and stuff." (Akeson et al., 2007)

The burden associated with managing a FA could influence whether adolescents would carry an AAI with them. A quantitative study identified a significant finding that adolescents who felt burdened by having to carry an AAI were less likely to carry it with them at all times (a form of disengagement coping) than adolescents who felt less burden ($z = 3.35$; $p = 0.001$; mean rank 22.64, 37.22, respectively) (Saleh-Langenberg et al., 2016).

FA could also affect how children and adolescents viewed their self- identity. For example, children who viewed their allergy more positively were more likely to be open about their FA with others and would also describe the foods that they ate and themselves as "special". Adolescents viewed their FA negatively as it made them stand out, dictated where they would go, what they would do, the friends they chose, and how they felt about themselves (DunnGalvin et al., 2009).

Behaviours indicative of secondary control coping strategies to manage the feelings associated with a FA identity were identified and were predominantly in studies of adolescents. Such strategies involved adaptation to FA, which included the use of acceptance or normalising the FA. Mackenzie et al. (2009) found that adolescents refused to let the FA 'place limits on their lives' (p. 599) and would frame the allergy positively, by focusing on what they were still able or wanted to do.

> *P14, female (18yrs): "It makes me more conscious of trying to be safe and trying to be prepared. But it doesn't stop me doing things… It makes me apprehensive about going out for meals and doing the odd thing, but it doesn't stop me doing what I want to do." (Mackenzie et al., 2009)*

Some adolescents would normalise the FA by embracing a social identity that included their FA. This was found to come more easily to those who could adopt a social identity with their FA by separating the "self" from the old identity and shifting to a new sense of self with their allergy (Fenton et al., 2011).

> *"Because in no way does allergies, EpiPens, and Medic-Alert define me as a person. Like sure, I have an allergy. That makes me no different than the person living up the street kind of thing." (Fenton et al., 2011)*

However, being able to normalise FA appeared to be associated with or influenced by the duration of diagnosis of FA (Mackenzie et al. 2007). Adolescents who had been diagnosed in early childhood had grown up with an awareness of their condition and how to manage it and were accepting of their FA as a way of life.

> *P15: "It doesn't really bother me because I've had allergies all my life… it's a way of life almost isn't it?" (Mackenzie et al., 2009)*

However, Mackenzie et al. (2009) found that the experience differed in those who had been diagnosed in later childhood and had a shorter amount of time to come to terms with their condition. Being diagnosed later appeared to be associated with the use of primary control coping strategies that were driven by anxiety, such as becoming hyper-vigilant, or disengagement coping strategies by being in denial of their condition.

Both Marklund et al. (2007) and Mackenzie et al. (2009) identified the use of social comparison amongst their adolescent participants, who would make downward comparisons by comparing their condition in the context of other problems. Some adolescents felt that their situation "could be worse", thereby adopting a more positive outlook. One such comparison reported by Mackenzie et al. (2009) was to people who were highly sensitive to their allergens.

P3: "There's some people that have to be really aware because they can just smell it and have a reaction. I'm kind of grateful for that." (Mackenzie et al., 2009)

Like theme 1, there was limited data pertaining to children aged 6 to 11 for this theme, and the strategies identified were largely those used by adolescents from the age of 12 to 19. However, a range of coping strategies that were associated with all three components of the CBMC when managing the emotional challenges that resulted from their FA were identified. Primary control coping strategies, such as increased vigilance and disengagement coping, such as avoidance, appeared to be a result of anxiety due to recent experiences of an allergic reaction. To manage the feelings of being different, secondary-control coping, such as cognitive reframing and normalising, and disengagement coping strategies, such as minimisation, were identified.

The level of anxiety felt and how children and adolescents perceived their own identity in the midst of their condition, may be facilitating or preventing the use of certain coping strategies. Duration of diagnosis may also have a role in the development and use of adaptive strategies or strategies that are triggered by anxiety and fear.

3.6.8. Theme 3: Seeking support from others

Ten studies referred to social support within their data (Akeson et al., 2007., DunnGalvin et al., 2009; Fenton et al., 2011; Gallagher et al., 2012; Jones et al., 2015; Monks et al., 2010; Macadam et al., 2012; Sommer et al., 2014; Stensgaard et al.,2017; Weiss & Marsac, 2016). Social support itself is a form of primary control coping (Compas et al., 2001). Two types of social support were identified within the included papers; emotional support and practical support. Sources of social support were found to come from family, peers, health care professionals and support groups.

As identified in Theme 1, social support played an integral role in coping with risk in certain locations. Parents in particular were an important source of social support for both children and adolescents. Differences were identified amongst the papers in the relationships children and adolescents had with their parents, and how parents were used as a means of social support. DunnGalvin et al. (2009) found that children had a natural reliance on their parents to help cope with their FA, for both psychosocial and practical management of the condition such as risk assessment, or managing social situations. Both DunnGalvin et al. (2009) and Macadam et al. (2012) identified the important role mothers had as they were seen as an "important safety mechanism". Mothers also tended to inform others such as parents, teachers and friends about their child's FA or took responsibility for their child's food at social events such as parties, as explained in Sarah's quote below.

Sarah (7yrs): "I'm fine because Mum brings my own food to parties." (DunnGalvin et al., 2009)

In contrast, adolescents appeared to have different experiences of seeking social support from their parents. Akeson et al. (2007) found that emotional support was not typically sought from parents, but

seeking practical support for issues similar to children remained. Using social support of parents was also identified if some adolescents felt safer under their parent's guidance in situations where higher levels of care to avoid allergens might be present, such as eating outside of the home (Sommer et al. 2014). Monks et al. (2010), Gallagher et al. (2011) and Gallagher et al. (2012) identified how parents supported their adolescent child by carrying medication and checking if food was safe in public places such as restaurants. Practical support was important if adolescents experienced challenges carrying their medication. As revealed in John's quote below, the support of parents was important when he struggled to carry his medication with him due to its size (Gallagher et al., 2011).

> *John (16yrs): "I think they're just too big, I've got to carry enough as it is, and I'd usually check before I eat stuff and if I didn't know about it so it's usually OK… If I'm with my parents they'll have it usually, but apart from that no, it usually just stays in the cupboard." (Gallagher et al., 2011)*

Parents also provided an additional form of social support for their adolescent child where they acted in a collaborative role to help with the transition of responsibilities of FA management, such as medication management and checking food ingredients (Akeson et al., 2007; Fenton et al., 2011; Gallagher et al., 2011). This could help adolescents feel more confident and independent in dealing with their FA when given more responsibility for managing it by their parents. It also appeared to help facilitate the use of more adaptive, primary control coping strategies. One adolescent demonstrated how their increased responsibility changed how they coped with their FA, demonstrating the use of primary control coping strategies (Fenton et al., 2011).

> *"But it has also made me take a lot more responsibility, because if I didn't have one (allergic reaction), I wouldn't really think about it, and now I think about stuff, and I am more responsible knowing that I have to bring my EpiPen with me, and read the labels, and everything before I do it." (Fenton et al., 2011)*

Approaching friends and peers for support was less commonly reported in adolescents, however, DunnGalvin et al. (2009) found that children below the age of 9 were more likely to tell others about their condition, which could influence whether support was sought from friends, and what coping strategies were used (DunnGalvin et al., 2009). In the same study, children and adolescents (identified as aged 9 and upwards) were more selective about whom they disclosed to, for example, only disclosing to 'best friends'. Selective disclosure became an issue when social relationships were challenging, and if the child or adolescent had been a victim of bullying or teasing because of their FA (Monks et al., 2010; DunnGalvin et al., 2009).

> *P16 (M13): "It's just one of those things which they just sort of brush aside. Maybe if they knew well this person could die or be seriously injured or whatever then they might, sort of take it a bit more seriously." (Monks et al., 2010)*

For some adolescents, many of their peers would not be aware that they had a FA and would only mention it if necessary, as illustrated in the quote by Peter below.

Peter: "I'd only mention something if it came up…" (DunnGalvin et al., 2009)

Hiding or not disclosing the FA to others, may have served the purpose of distancing oneself emotionally or cognitively from the stressor of FA, a form of disengagement coping.

In the study by Stensgaard et al. (2017), adolescents described the challenges of making friends, and three of the five adolescents interviewed had experienced bullying in relation to their FA. DunnGalvin et al. (2009) and Monks et al. (2010) found that some adolescents felt that coping with a FA at school would be easier if their peers understood their condition and took it more seriously. This could also influence how adolescents coped, as those who had negative experiences with their peers described behaviours indicative of disengagement coping such as not disclosing their FA to others.

Healthcare professionals (HCP) and allergy support groups were identified as sources of practical social support, though data was limited and only identified in four papers. Access to an appropriate HCP varied, with some fortunate to have access to an allergy specialist and others reporting no contact once discharged from an allergy service or receiving little to no support or input from their GP (Gallagher et al., 2012). Despite the variation in accessing a HCP, the support received from a HCP could influence the way adolescents managed their FA and could be an invaluable source of support, as Claire describes in her quote below.

Claire (16yrs): "She's really nice, she like, every time I go up if I have a problem wi' something then she'll go through it, she'll explain it and stuff like that, and she really does help." (Gallagher et al., 2012)

One study mentioned the use of support groups. Jones et al. (2015) found that 31% of adolescents in their study (aged from 13-19 years old) belonged to an anaphylaxis or allergy support group. Being a member of a support group correlated with adherence to desirable self-care behaviours for their FA which were indicative or primary-control coping, such as allergen avoidance and carrying emergency medication ($r_{pb} = 0.25$, $p = 0.001$). A logistic regression analysis further demonstrated that adherence to self-care behaviours was greater in those who belonged to a support group (OR = 2.54, (1.04, 6.20) 95% CI). These results demonstrate that support groups could have an impact on self-care behaviours that are indicative of primary-control coping, however, it was not clear whether support groups were based around peer support, or run by healthcare professionals.

In summary, social support was identified as coping strategy used by both children and adolescents. Differences were identified between how children and adolescents used social support, which appeared to be associated with age and also the transition of responsibilities in adolescence. Seeking support from friends and peers was reported by younger children but was not reported frequently by older children, or adolescents, due to concerns that disclosing FA status could make them stand out and become a potential target for bullying or teasing. A lack of understanding from friends and peers was also seen as a barrier to development and use of adaptive coping techniques such as social support to help them cope.

Social support itself can facilitate the development of adaptive coping strategies, whether this is working collaboratively with parents to hand over more responsibility to adolescents, or through education from HCP's or support groups. Individuals in studies who received regular contact with HCP's, such as doctors, had greater levels of adherence to self-care behaviours such as carrying an AAI.

3.6.9. Theme 4: Carrying and using adrenaline-autoinjectors (AAI)

Carrying and using AAI has been identified as an important primary control coping strategy to manage the risks associated with FA and being able to treat an allergic reaction. However, within this theme disengagement coping and secondary-coping strategies were also identified surrounding the carriage of AAI's. Eight studies discussed the issue of AAI's (Akeson et al., 2007; Gallagher et al., 2011; Gallagher et al., 2012; Jones et al., 2015; Macadam et al., 2012; Monks et al., 2010; Saleh-Langenberg et al., 2016; Stensgaard et al., 2017). The majority of participants of the studies included in this theme were adolescents from the age of 12, with only one study including younger children of 11 years of age (Monks et al., 2010).

Many adolescents recognised the importance of their AAI and carried it with them (Akeson et al. 2007, Gallagher et al., 2012; Saleh-Langenberg et al., 2016), with many also reporting high confidence in their ability to use their AAI (Jones et al., 2015). Generally, adolescents carried their medication with them when in high-risk or unfamiliar locations, such as during school trips, whilst travelling or on holiday, and when eating outside of the home (Gallagher et al., 2011; Gallagher et al., 2012; Monks et al., 2010; Saleh-Langenberg et al., 2016; Stensgaard et al., 2017).

But, despite the advice to always carry an AAI, there were instances when AAI's were not carried or used. The decision to carry an AAI could depend on the adolescent's perceived need to do so under various circumstances (Saleh-Langenberg et al., 2016). Some would leave their AAI at home if they were in familiar locations, locations close to home, or if adolescents didn't expect to be eating (Gallagher et al., 2011; Macadem et al., 2012; Stensgaard et al., 2017).

The size and design of the AAI appeared to be a contributing factor in deciding whether or not carry medication. For example, many felt that, due to its size, the device was awkward to carry (Akeson et al., 2007; Gallagher et al., 2011). Therefore, adolescents sometimes made the decision to not carry their AAI or leave it at home (Gallagher et al., 2011; Monks et al., 2010; Macadam et al., 2012; Saleh-Langenberg et al., 2016). The inconvenience of carrying medication is illustrated in Chris' quote below.

> *Chris (16yrs): "I carry it most of the times when I'm out of the house, most of the times when I'm like going into town or going to parties and such like, but if I'm just going like down to the shop or something like that I don't normally take it because it's just like an encumbrance generally." (Gallagher et al., 2011)*

Four studies made references to the differences between genders on coping with AAI carriage (Akeson et al., 2007; Gallagher et al., 2011; Gallagher et al., 2012; Macadam et al., 2012). Adolescent boys (aged

12 and upwards across the four studies) described more difficulties with carrying their AAI than girls as boys were more limited in their methods of carrying their AAI. This is illustrated by Steven in his quote below.

Steven (19yrs): "It's just the sheer hassle of having to take it, you know, it's like, I mean they're quite big and they don't fit in any of my pockets." (Gallagher et al., 2011)

Monks et al. (2010) found that many adolescents in their study would be happy to carry their AAI more frequently if their device was smaller.

Coping strategies were identified in the studies which were used to facilitate AAI carriage. Secondary control coping strategies were identified in a study by Macadam et al. (2012), where some adolescents used positive reinterpretation to balance their negative feelings against the perceived advantages of having an AAI on them. This is demonstrated by Rebecca who says that despite the inconvenience, she believes it is important to have her AAI.

Rebecca: "It can be awkward at times to carry… I don't mind though, it's important obviously so it's one of the things you just have to deal with." (Gallagher et al., 2011)

The attitudes of friends and peers was a factor identified by one study that could influence the use or carriage of an AAI (Macadam et al., 2012). Some adolescents had friends who had no understanding of FA, and who saw the AAI as something to make fun of, play around with or steal which could place a negative emphasis on medication. But adolescents who had positive reactions from friend and peers, had greater acceptance of their AAI and felt more comfortable about carrying their AAI's; even teaching their friends how to use an AAI, both examples of primary-control coping. This is illustrated in the quote below by an adolescent participant.

F16: "Like all my friends know how to use it. Yeah, like ehrm they would like come round home, like a few of my friends, so we can use an out-of-date "auto-injector" on oranges and stuff like that." (Macadem et al., 2012)

Knowledge of AAIs and how to use them appeared to be both a barrier and facilitator to their effective use, and how adolescents coped if they needed to use one. Whilst some adolescents understood when to use their AAI, Gallagher et al (2012) identified two factors that were found to be important in AAI use; 1) knowing when to use the AAI; 2) the training received regarding AAI administration technique. Jones et al. (2015) found that only 17% of adolescents in their study were able to identify all of the steps to correct AAI administration; 44% were incorrect about how to hold an AAI, and 32% were incorrect about seeking medical advice following administration of an AAI in case of a "biphasic reaction"[1].

In some cases, adolescents sought social support by preferring parents to administer their AAI for them (Monks et al., 2010). Other's did not use their AAI as they misunderstood when to administer it, despite

[1] A biphasic reaction is a potentially life-threatening recurrence of symptoms of anaphylaxis after initial resolution of an anaphylactic reaction, which can occur without re-exposure to the trigger. Lee, Bellolio, Hess, Erwin, Murad & Campbell, (2015).

a reaction taking place or confusing it with another illness such as asthma, as Sophie explains in her quote below (Gallagher et al., 2011).

> *Sophie (19yrs): "I thought I was having an asthma attack, which is really scary because like I thought if I had an anaphylactic shock I would be throwing up, because that's what it was when I was little, that's why I didn't use the EpiPen because I didn't know what I was having." (Gallagher et al., 2011)*

Many felt that improved practical training or regular refresher training would help them know when and how to use their AAI. Some adolescents felt that knowing what it would feel like to administer an AAI could enable them to develop effective strategies in using their medication (Monks et al., 2010).

> *M13: "I also think, like, maybe one of those Annie's that you get, you know the ones you learn CPR on? Well if you can get, like, Annie legs and maybe do it on that and actually have, like, a real injector so you know what it feels like to do it." (Monks et al., 2010)*

The studies that contribute to this theme of AAI use mainly consisted of adolescent participants (aged 12-19), with only one study (Monks et al., 2010) having participants younger than that, including those aged 11 years. There were no views on AAI use explicitly by children below the age of 11. Though using an AAI is indicative of primary control coping as this strategy would enable one to be able to treat an allergic reaction, other coping strategies associated with its use were identified. Social support could help to facilitate AAI carriage or use via the support of parents and educating friends and peers about the AAI. Secondary-control coping was identified in one study Macadam et al. (2012), where adolescents were able to balance the positives and negatives of having to carry an AAI. Barriers and facilitators to AAI carriage and/or use was found to be dependent on factors ranging from the location or situation an individual was in or other people's attitudes. The size/shape of the device could also be a barrier, with adolescents adopting maladaptive coping strategies to cope with this, by not carrying their device with them. Knowledge was also a barrier, as for some participants, a lack of understanding around recognising when anaphylaxis was taking place, led to a delay or failure in administering their AAI, and poor knowledge around AAIs was also evident.

3.7. Discussion

This systematic review synthesised the data of fifteen studies published between 2007 and 2017, adopting a narrative synthesis approach to explore the findings. Of the included papers, two specified investigating coping strategies in this population (DunnGalvin et al. 2009; Weiss & Marsac, 2016), with the remaining papers investigating the experiences of those living with FA or anaphylaxis, the impact of living with a FA, and using AAI's. Though not all of the papers specifically studied coping, there was sufficient information provided in the narrative to allow for an analysis of coping behaviours.

Four themes were identified; 'coping with food allergy: navigating different locations'; 'coping with the emotional burden of FA'; 'seeking support from others' and 'carrying and using adrenaline-autoinjectors (AAI)'. Within these themes, an attempt has been made to understand the types of coping

strategies that have been used and what factors act as facilitators or barriers to adaptive coping. From the analysis of the data of the included studies, it appears that children and adolescents use a range of strategies to cope with their FA, and using the CBMC, these can be categorised as either primary-control coping, secondary-control coping or disengagement coping.

The theme *'coping with food allergy: navigating different locations',* explored the precarious process of coping with a FA, with a particular emphasis on location. Primary control and disengagement coping strategies such as social-support or avoidance were used in high-risk locations such as restaurants and schools. For adolescents, it appeared that familiar locations could lead to disengagement coping and risk-taking behaviour, where adolescents calculated the need to carry their AAI based upon the familiarity of their location or situation they were in. Coping with risk appeared to differ depending on the ages of the participant; children relied more on the support of parents whereas adolescents took more calculated risks. Though studies including children below the age of 11 in the review was limited, the three studies that included participants below this age (DunnGalvin et al., 2009; Fenton et al., 2011, Weiss & Marsac, 2016), found that younger children had greater dependence on parents to cope with their FA. Adolescents, on the other hand, were found to be responsible for making their own risk assessments, which was similar to the findings of a study by Warren et al. (2017), where adolescents with chronic illnesses were expected to assume greater responsibility towards self-management, indicating increased independence.

The difference identified between the ways children and adolescents coped with their FA may lie in the amount of independence (and therefore reduced parental oversight) an adolescent has in comparison to a child. Parental monitoring has been found to be a strong predictor of adherence among adolescents and was identified in a study by Sampson et al. (2006) (excluded from this review due to the age range of participants) where higher rates of medication carriage occurred in situations where there was more parental oversight. This could suggest that reduced parental monitoring and increased independence may explain why adolescents were found to engage in more risky behaviours, or why some adolescents adopted the use of disengagement coping strategies such as avoidance compared to children who may have been in more consistent contact with family.

The theme *"coping with the emotional burden of food allergy"* explored the effect FA could have on the psychological wellbeing and emotions of children and adolescents and the types of strategies used to cope with this. Only two studies provided some explanation of how children and adolescents coped with specific psychological difficulties; anxiety (DunnGalvin et al., 2009) and PTSS (Weiss & Marsac, 2016). Other studies touched upon emotions more broadly, using terms such as 'negative feelings' and 'emotional burden'. More secondary control coping than primary-control or disengagement strategies were identified, such as using social comparisons or positive reinterpretation. This is possibly due to the purpose of this form of coping to adapt oneself to the stressor, which has been suggested to be effective in successful adaptation to chronic illness (Compas et al., 2012).

Secondary control coping strategies have been found to reduce symptoms of anxiety and depression and lead to greater wellbeing and better adjustment in children and adolescents with type 1 diabetes, chronic pain and cancer (Band & Weisz, 1990; Compas et al., 2006; Edgar & Skinner, 2003; Hocking et al., 2011; Miller et al., 2009). These studies used measures that incorporated the three-factor framework of the CBMC and included other measures of outcomes such as depressive symptoms. In some cases, health-related outcomes were measured, such as HbA1c levels, that could be analysed in relation to the types of coping strategies used. The only quantitative study in this theme (Weiss & Marsac, 2016) did not use an outcome measure based on the three-factor framework, and the data provided in the article was not detailed enough to examine the types of coping behaviours used and the effect of these coping strategies on PTSS's outcomes. The remaining studies were qualitative and did not specifically measure coping, nor measure outcomes such as anxiety or depressive symptoms, a possible explanation for a lack of identifiable primary control and disengagement coping strategies to deal with emotions in this review. However, it could be possible that participants in the included studies appraised their FA to be more controllable than not, which may have limited the identification of disengagement type coping strategies in this theme. Given the evidence for the efficacy of secondary control coping with adaptation to illness, such as diabetes (Band & Weisz, 1990) and fewer symptoms of anxiety and depression in those with chronic pain and diabetes (Edgar & Skinner, 2003;. Hocking et al., 2011) further exploration is needed to fully understand the role of secondary control coping on psychological outcomes or adaptation to FA.

The theme *'seeking support from others'* discussed the role social support, a form of primary-control coping, played and identified two types of social support; emotional support and practical support. This theme is unique, as though social support was a coping strategy identified across theme 1 and theme 4, distinctions were identified across how these types of social support were used across the age range, and who was accessed for social support. Both children and adolescents sought the support of parents as a way of coping with their FA, however, seeking emotional support was identified more in younger children than adolescents, with mother's playing a significant role in coping with FA. The reliance of children on their mothers, and the dominant role of mothers has been highlighted across FA studies, including studies that were excluded from this review (LeBovidge et al., 2008; Sanagavarapu, 2017). Adolescents were not found to seek this type of support from parents and appeared to have a different experience of parental social support that was more collaborative in nature. However, there was little from the data in the included studies to further explore the use of emotional support as a coping strategy in adolescents.

Seeking support from friends was not widely reported in the data analysed, though both children and adolescents were sensitive about how their friends or peers perceived the seriousness of their condition or their particular needs. Adolescents appeared to be more sensitive to how their FA may be perceived by their peers in contrast to children, though this is also possibly due to the lack of included studies that

sampled participants below the age of 11. This self-protective strategy of not talking about their FA with their peers was similar to findings identified in a review of children and young people's experiences of living with a chronic condition by Lambert and Keogh (2015). In their review, studies that identified selective disclosure had participants with ages ranging from 7 to 24 years old (Admi & Shaham, 2007; Lewis & Parsons, 2008; McEwan, Espie, Metcalfe, Brodie & Wilson. 2004; Moffat, Dorris, Connor & Espie. 2009; Wang, Brown & Homer, 2010) with little to no differentiation identified between how children and adolescents disclosed their condition and to whom. However, in the context of FA, DunnGalvin et al. (2009) only found selective disclosure in children aged 9 and upwards. Whilst it is unlikely that there is a specific age where attitudes towards disclosing to friends and peer's changes, it does suggest that along the developmental process there is a shift in identity and how a child or adolescent perceives themselves within the social context of their group which could affect whether disclosure to friends is made, and ultimately, whether the support of friends can be sought. Additionally, children and adolescents with chronic illness can experience isolation which can hinder the development and maintenance of friendship, resulting in greater dependence on parents (Christie & Khatun, 2012). This could help to explain why the support of friends were rarely sought or perhaps reported as a coping strategy in this review.

Support from HCPs and support groups was not often reported in the data and what participants were offered or had access to appeared to vary. Having a good level of support from healthcare professionals is important, and variances in professional support may have a negative impact on coping as studies have shown that visits to a multidisciplinary clinic can improve families' abilities to manage the child's FA and reduce the number of allergic reactions (Kapoor, Roberts, Bynoe, Gauhan, Habibi et al., 2004). Very few reported attending support groups, and it may be possible that support groups are attended by parents rather than by the child or adolescent. However, the benefits of support groups in providing peer support, education and developing coping strategies has been identified in both adults with FA (Coulson & Knibb, 2007) and young people aged 12-21 years old (Jones, Sommereux & Smith, 2018). Jones et al. (2018) found that support groups gives individuals the opportunity to feel included and share their experiences with others with similar problems or challenges. They can also positively influence adherence to self-care behaviours. Given the limited information regarding the use of support groups within this review, and the benefits that support groups can have, further investigation into the use of support groups as a coping strategy in this age group would be helpful to establish whether they are widely used as a way of coping, and whether these can be helpful as both a coping strategy and as a facilitator to learn coping strategies.

The theme *"Carrying and using adrenaline auto-injectors - AAI"* highlighted the importance that the device has for safely coping with a FA, yet the use, knowledge and carriage of the device varied greatly. Knowledge and training were key factors in this theme, and poorer knowledge regarding the device could lead to a lack of confidence in using the AAI and relying on the support of parents. As education

has been shown to improve adherence (Rapoff & Lindsley, 2007) repeated education is important for individuals with FA, especially if diagnosed at a younger age where information may have been initially targeted at parents, rather than the child (Taddeo, Egedy & Frappier, 2008). However, effective use or carriage of an AAI could also be dependent on the situation or environment, and whether it appraised as high or low risk, which was similar to the findings of the study of food allergic adolescents and young adults by Sampson et al (2006). Friends and peers' attitudes towards the device could also affect medication carriage. This was particularly identified in studies with adolescent participants and reflected what previous themes had found regarding identity and peer relationships having an effect on how FA is managed.

Another possible explanation in the lack of use and carriage of an AAI, may be due to whether an allergic reaction has been experienced or not. In the studies included in this theme there was a lack of information regarding previous experience of anaphylaxis by participants in two of the studies (Gallagher et al., 2012; Macadam et al., 2012) whilst information in the remaining studies was broad, for example, only stating the number of times a reaction was experienced within a certain time frame. Jones et al (2015) found that adherence to self-care behaviours in food allergic adolescents may be explained by whether anaphylaxis had been experienced or not. Long periods of time since symptoms or an allergic reaction were experienced could give a misleading impression that they are no longer affected, or at a reduced risk, which could affect self-care behaviours.

3.8. Strengths and limitations

To my knowledge, this is the first systematic review to study how children and adolescents cope with FA. A strength of this review is the way that evidence has been synthesised, which has resulted in the emergence of themes attributed to coping strategies which were not apparent from the primary studies such as coping with emotions, coping with FA in different locations, and the roles of social support and AAI's as coping strategies. This review helps to improve understanding of coping strategies used in children and adolescents with FA. Another strength lies in using the CBMC to identify coping strategies and behaviours within the data. No papers included in the review used a specific model of coping, though the application of the Health Belief Model (Jones et al., 2015) was used to understand adherence behaviours. The review includes participants from a broad age range, and as well as being able to identify the coping behaviours of children and adolescents, it highlights some of the barriers and facilitators to how children and adolescents cope with FA. Finally, a strength of the review was the use of abductive analysis to combine data drawn from the studies with an established model of coping, which helped to provide a fuller and richer understanding of the ways in which children and adolescents cope with their FA that would not have been obtained from inductive or deductive reasoning alone.

There are, however, limitations to this review. Firstly, only qualitative data that the primary authors chose to report from their data and an interpretation of the primary authors' interpretations of their

participants' accounts could be analysed - a triple hermeneutic (Smith, Flowers and Larkin, 2009). Additionally, only two papers specifically explored coping behaviours, with the remaining papers exploring AAI use and experiences of living with FA. Although the process of data extraction and the development of the themes was regularly discussed and reflected upon within the research team, further collection and analysis of primary data is needed to support the findings from this review. Secondly, only three studies included children below the age of 11. Therefore, it is difficult to fully appreciate how children below this age cope with FA, particularly with themes that had predominantly adolescent data. Further primary data is required from children below the age of 11 to understand their coping strategies and how these may differ from adolescents, if at all. Drawing conclusions from this review to understand how children below this age cope with their FA should be approached with caution at this stage. Lastly, I was the only person to conduct the searches for the studies and it is possible that potentially eligible studies were missed in the initial search process despite the systematic method of searching for eligible papers.

3.9. Conclusion

This systematic review identified a small number of studies and through qualitative analysis was able to explore and explain the different ways that children and adolescents cope with their FA. Only two papers specifically examined coping in children and adolescents with FA, with remaining papers more broadly exploring AAI use and the experiences of living with FA. This review demonstrates that coping with a FA is a complex and multifaceted process, and many factors can influence what types of coping strategies are used. This can be due to factors such as location and its perceived risk, and age. However, it is still not clear how exactly this population copes with a FA as interpretation and analysis could only be conducted on the researchers' interpretation and analysis of their participant's words. The analysis of primary data that specifically focusses on how children and adolescents cope with their FA would be beneficial to further investigate this. Additionally, only three papers included children below the age of 11 and further investigation with children below this age will help researchers and healthcare professionals understand how children below this age cope. The next two chapters address these gaps in the literature.

CHAPTER 4 Understanding coping strategies used by children aged 8-11 years old with food allergy – a thematic analysis

4.1. Overview

In this chapter, I outline the findings from a series of interviews conducted with children aged 8-11 years old with a diagnosis of food allergy (FA). This age range was chosen after reading through the transcripts which showed that 8-11-year olds faced different issues to adolescents aged 12-16 years old (see Chapter 2, section 2.6.2, for the rationale behind the analysis of this age group). The aim of this chapter was to explore how children in this age group coped with their FA. This study and analysis were underpinned by a CBMC (Compas et al., 2001) which helped to categorise coping behaviours in the context in which they were identified. Full details about the methodology used are described in Chapter 2.

4.2. Background

Research has shown that explaining coping in children can be unique and challenging as children can have divergent views from adults about the cause, aetiology, treatment and strategies required to deal with illness or disease (Schmidt, Petersen and Bullinger, 2003). Whilst chronic illness can be perceived to be stressful at any age, in childhood it can be particularly challenging as 'normal' childhood development already contains a number of day-to-day activities and socialisation challenges. FA has been known to impact a child's experience of QoL, such as placing restrictions on physical activities, when compared with healthy children, or children in other illness groups such as Type 1 diabetes (Avery et al., 2003). FA can have a negative impact on mental health, such as a vulnerability to develop anxiety (LeBovidge et al., 2009), on their friendships by being isolated from others, and on their identity and self-confidence for being perceived as different (Evans & Rouf, 2014). Despite awareness of these challenges, there remains a lack of research conducted to explore how children with FA cope with these issues.

A developmental review into coping by Zimmer-Gembeck and Skinner (2011), suggested that young children primarily sought support from caregivers, and as they started school, begin to use more cognitive strategies such as problem-solving and distraction. This was similar to the findings of the systematic review in Chapter 3, which emphasised the level of dependence children had on their parents to cope with their FA (DunnGalvin et al., 2009; Fenton et al., 2011). Skinner and Zimmer-Gembeck (2007) also stated that older children became more selective about who they would approach for support and were able to modulate their own emotional states through positive self-talk and cognitive reframing. They further stated that the capacity to use particular coping strategies, such as decision making and planning, may not fully emerge until late adolescence or early adulthood. Only three studies in the

systematic review (Chapter 3) included children below the age of 11, and as such, it was difficult to establish if children used additional coping strategies to those used by adolescents.

Within the wider FA literature, few studies have focused on the types of coping strategies used by children with FA, and of those that have, none have applied an established coping model to explain the strategies. A recent study by DunnGalvin et al. (2018) sought to investigate the applicability of a developmental model based on earlier work (DunnGalvin et al., 2009) and conducted deductive thematic analysis on secondary data from interviews with children, adolescents and young people aged 6 to 23 years old across five countries to understand how they cope with FA. Their findings suggest that early-life experiences with FA, could provide the foundation for later behaviours, and that emotions attached to living with FA (such as embarrassment and fear) can drive a search for "normality" that can influence the use of particular types of coping strategies such as 'maximisation' which includes extreme avoidance, hypervigilance and constant planning or 'minimisation' which includes deliberately not thinking about FA, not carrying an AAI and not telling others of the FA. However, there can be methodological challenges with conducting secondary analysis on qualitative data. In particular, the extent of the difference between the research question of the primary study and that of the secondary study (Hinds, Vogel & Clarke-Steffen, 1997).

If specific coping strategies are unique to children with FA compared to adolescents, these need to be identified, and further primary data needs to be collected that specifically focuses on coping. Therefore, to bridge this gap in the literature, a qualitative study exploring the coping strategies used by children at 8 to 11 years old with FA was conducted, underpinned by the CBMC.

4.3. Aim

The aim of this study was to explore and understand the types of coping strategies used by children with FA and what context these strategies are used in, applying a CBMC to identify and understand the strategies used. The age range of 8 to 11 years old with a FA followed a retrospective decision after interviews were conducted with children and adolescents aged 8-16, where differences were identified between children who attended primary school and those who went to secondary school.

4.4. Study Design

This was a qualitative study, using semi-structured interviews. Ethical approval was granted by the South West and Frenchay Research Ethics Committee (15/SW/0316 – 26/10/2015).

4.5. Study Setting

Semi-structured interviews with children aged 8-11 years old were conducted either face-to-face at Aston University, in a private room in their home, or via a video-calling method using Skype. Locations were chosen by the child and their parents. Parents were not present during the interview.

4.6. Recruitment

The study was advertised via the allergy clinics at the Sandwell and West Birmingham NHS Trust. As described in Chapter 2, it is important to note that the advertisement was for children and adolescents aged 8-16 years old. Due to a low uptake of interest from patients who attended these clinics, the study was also advertised by the charity Allergy UK via their website, newsletter and social media platforms. Parents of children who expressed an interest in the study were asked to contact me for more details of the study and those who did were sent an information pack which contained information sheets for the child and parent (Appendix 7 & 8). Information packs were posted or emailed to the parent depending on their preference. If the child wished to take part in the study, parents were asked to contact me to arrange a time and date to be interviewed.

4.7. Participants

Thirteen children (n= 8 males, n=5 females) aged 8-11 years old participated in the study. The mean age was 9.8 years old. Of these, n=10 participants were recruited via advertising by Allergy UK, and n=3 participants recruited from an allergy clinic at City Hospital, Birmingham. Four participants were interviewed face-to-face (two at their home, and two at Aston University), and nine participants were interviewed using Skype.

All children had been prescribed an adrenaline auto-injector and antihistamines in either liquid or tablet form. Allergies to other types of nuts was the most common reported FA (n=11), followed by peanuts (n =10). Only one child had been diagnosed with a single FA, with the other children diagnosed with multiple FA (Table 4.1). Twelve children were White-British, and one child British-Asian.

4.8. Procedure

The date, time and location of the interview was decided by the child and his or her parents. Signed consent forms (Appendix 9 and 10) were either obtained at the home of the child, or if conducting the interview via Skype, consent forms were emailed to the parent for them to complete with their child and posted back to me before arranging an interview date. Prior to starting the interview, I checked that the child understood the nature of the study, reassured them their information would remain confidential and that they were free to withdraw at any time. A checklist was completed with the child and parent about their FA (Appendix 11). An interview schedule was used to guide the interview (see Appendix 12) and all interviews were recorded and transcribed verbatim.

Table 4.1: Participant characteristics

Gender	Age	No. of allergies	Peanut	Other nuts	Cow's milk	Egg	Soya	Fish	Shellfish	Latex	Tree pollen	Grass pollen	Other
F	8	2	x										x
F	8	14	x	x	x	x	x	x	x	x	x	x	x
F	9	10	x	x	x	x	x					x	x
F	9	6	x	x	x	x	x	x	x		x	x	
F	10	6		x	x	x			x		x	x	x
M	10	4	x										x
M	10	10	x	x	x	x	x						x
M	10	6	x	x							x	x	
M	10	6	x	x		x	x						x
M	11	5	x	x	x						x	x	x
M	11	5	x	x		x	x				x	x	x
M	11	3		x	x								
M	11	1		x									

4.8.1. Interview schedule

An interview schedule was used to guide the interview (Appendix 12). Whilst the schedule acted as a topic guide, there was flexibility in the interview process to allow for conversations and topics to develop naturally with the children interviewed.

4.9. Analysis

The transcripts were analysed thematically using an abductive approach. Coding was primarily inductive, focussing on the experiences of the child and their descriptions of behaviours used to cope with being allergic to food. This was followed by deductive thematic analysis by comparing the coping behaviours identified during inductive analysis with the three components of the CBMC to provide a contextual explanation to the findings. For each child, coping strategies identified within quotes were categorised using the CBMC as either primary-control, secondary-control or disengagement coping (Appendix 13) before being combined with data from the rest of the participants (Appendix 14). Abductive reasoning took place through a recurring process of conducting inductive and deductive analysis on the transcripts, with the process and findings discussed with the supervisory team as part of a reflexive process. A reflexive diary was kept to record my thoughts and experiences during the interview and analysis process. These helped to shape my understanding of how my own experiences of working with children with chronic illness shaped my interpretation and analysis.

4.10. Results

Four themes emerged from the data: ‘Staying safe in high and low-risk places’, ‘Not knowing enough about food allergy’, ‘How being allergic to food makes me feel, and what I do to feel better’; ‘I have a food allergy, but I still think I’m like my friends’. In the written analysis, all participants are identified by pseudonyms along with their age, e.g. ‘Sarah (8yrs)’. Coping strategies identified in the data were classified using the CBMC as either primary control, secondary control or disengagement coping.

4.10.1. Theme 1: Staying safe in high and low-risk places

Children associated risk with an allergic reaction and dichotomised places or situations as either high-risk or low risk, with no locations rated in between. High-risk places were those that were deemed unpredictable or unsafe, where children perceived they had a higher chance of an allergic reaction, and where control was difficult to maintain. In contrast, places defined as low risk were those associated with familiarity and safety, a place where the chance of an allergic reaction was low, and the perception of control was higher. How children coped with their FA to avoid an allergic reaction depended on their perception of risk and safety.

Low risk/Safe

The home was most commonly perceived to be a safe and low-risk environment due its familiarity and allergen free policy, which reduced the risk of an allergic reaction:

"I just feel safe because it's home and it won't have food there that will make me react" – Jasmine (9yrs)

Children felt comfortable living in this controlled and safe environment due to assumptions that their parents would keep them safe by providing safe foods for them to eat and a safe environment. Many children spoke of a strict allergy free policy, where even healthy siblings could not bring in food that contained an allergen into the home. Because of this assumption of others to provide an environment of safety and the perception of home being low-risk, children felt that they didn't need to read food labels or actively avoid unsafe food as this was already done for them, which contrasted with high-risk environments where such strategies were necessary to avoid an allergic reaction:

"It's like, so at home I'm like less careful with my allergies compared to school because I know what we have, and Mum will buy the same stuff every time, so I don't need to read the packets because I know it's fine. At school, though I would if I had to because that's different, that's a bit like sketchy." – Mike (11yrs)

Children still however, experienced uncertainty in places they perceived to be safe. An example of this was identified in the context of a friend's home. Elliot perceived the risk of an allergic reaction as higher compared to his own home, as he felt that his friend's parents would not be fully able to control the risk like his own. Elliot coped with the uncertainty by taking his medication with him, demonstrating that he was mindful of the possibilities of an allergic reaction. However, in contrast, Francis felt that his friend's home was as safe as his own as his friend and their parents were aware of his allergy and perceived the risk of a reaction to be low. Francis chose to leave his medication at home, justifying that the low risk and familiarity of his friend's home negated the need for him to carry his medication with him:

"Yeah, I generally feel safe at my friend's house, but it's like, it's not like home where I know having a reaction isn't going to happen. It could happen at my friends, so I'll take my EpiPen with me just in case." – Elliot (10yrs)

"If I'm going to my friend's house, he only lives down the road from me, I won't really bother to carry my EpiPen on me because it's normally fine when I go there so I don't need it, I feel like I can manage it fine there." – Francis (10yrs)

This demonstrated that, children could have different perceptions of what they consider to be low risk, which could affect how they coped with their FA.

High-risk/Unsafe

Outside of the home, the perception of risk changed along with how children coped with the risk. Children were very aware that their safety was compromised, and that the likelihood of an allergic reaction was higher. Compared to the home, some children felt less in control of their FA as factors outside of the home, such as members of the public, added to the uncertainty as Jacob illustrated:

"I don't feel like I can control my allergies when I'm not at home, everywhere else there's always people around and its really random, I don't know if I'll have a reaction or not." – Jacob (11yrs)

Keeping safe in high-risk places was largely achieved by a greater dependence on parents to provide instrumental support. Children relied on their parents to cope with the practicalities of FA management in high-risk places such as carrying medication and, if eating outside of the home, taking responsibility for informing staff about their child's allergy and ensuring food was safe to eat. Many felt that parents were more able to control the unpredictability associated with high-risk places as Emma explained:

E: "Mum is better at doing everything than me, I think. Especially when we go out, she knows what to do and she carries my medicine and stuff."
I: "Do you feel safer if your Mum does everything for you when you go out?"
E: "Yeah because I don't know what could happen and she would know what to do."
– Emma (8yrs)

Children depended on parents to carry their medication for them when going out as it was often more practical for them to do so. The majority of children did not have any means of carrying their own medication, such as Jack:

"My EpiPen is too big to fit in my pockets, so it's just better if my Mum carries it for me."
– Jack (10yrs)

In some cases, parents had a dominant role in managing their child's medication because they had always taken responsibility for it as Hannah described below:

"Mums always carries the EpiPen when we go out." – Hannah (9yrs)

Occasionally, it was not carrying medication that was a challenge, but the responsibility of remembering to carry medication that could be problematic which could negatively impact the day as Francis explained below. However, he reflected on not being used to managing his own medication which he felt could cause him to forget it:

"Once we had to come back home on the motorway because I forgot the EpiPen, which was annoying. But I'm not really used to carrying it, so I think that's why I forgot it."
– Francis (10yrs)

One child explained having a bag that he carried with him everywhere, placing him in charge of his medication:

"I have like a special bag, like a bum bag for my medicines so I can wear that when I go out with my Mum or to my friends' houses and stuff and it makes it easier for me to have my EpiPen and inhaler and stuff." – Elliot (10yrs)

Restaurants and schools were largely identified within the data as high-risk places. Children perceived both places to have greater exposure to food and less control than the home, which equated to a greater risk of an allergic reaction. The majority of children depended on their parents to cope with risk in restaurants by alerting staff about their allergy, asking for specific allergen menus or by ensuring that their immediate surroundings were safe. In addition, children such as Sarah and Christopher believed that their parents would be better at managing these things than if they were to do it themselves:

"I normally get Mum to tell them I have an allergy and I need a special menu and stuff because I don't think I could do it." – Sarah (8yrs)

"Usually Mum and Dad check the restaurant and the food and the tables and everything because they're really good at it, better than me." – Christopher (10yrs)

Children didn't have confidence in their ability to keep themselves safe in high-risk places, comparing the high-risk of restaurants with the safety of their own home as Sarah illustrated below:

"I don't worry at home because Mummy cooks things that I can eat, but when we go to a restaurant, I don't know what they'll use, and I get worried about it and I don't know if I can keep myself safe." – Sarah (8yrs)

When probed further, it appeared that the trust they had in their home could not be reflected anywhere else as parents were now no longer in total control of their environment:

"Mum looks after everything in the house, and does the shopping and doesn't bring anything home with nuts and stuff. But in like Pizza Express and stuff, someone else is doing everything." – Jack (10yrs)

When eating out with the family, children described only visiting familiar restaurants. In an environment where the potential for an allergic reaction was higher, children were able to exert some control by only ordering what they had eaten before and knew was safe:

"We always go to the same Chinese place and I'll always have the plain rice and plain chicken always" – Elliot (10yrs)

Familiarity appeared to equate to control and safety as children knew what to expect when it came to their surroundings and the food, and were used to the routine and environment. However, in one incident, Mike described visiting a familiar restaurant to find the menu had changed and his regular dish no longer on the menu. This disrupted Mike's feeling of confidence who felt that he had to "start again" to gain the trust of the restaurant and of his parents in choosing something suitable for him to eat:

"One time we went to eat where we always go, and they changed the menu and my chicken dish wasn't on there. And I thought I have to start again to find something I know I can eat, and how do I know what my Mum says I can have is ok and whether the restaurant will make sure it doesn't have nuts and dairy in and stuff. It was, it was just, I was really worried about it." – Mike (11yrs)

One child described never eating outside of the home at restaurants. When asked if this was her choice, Jasmine explained that it was her parent's decision not to eat out. It appeared that her parents believed the risk of eating out was too great, which was then reflected by Jasmine who now believed that eating outside of the home at restaurants would only enhance her chances of an allergic reaction:

"Mum and Dad don't think it's safe, so I don't think it would be safe to go out to eat because I'll have a reaction." – Jasmine (9yrs)

School, though high-risk, was perceived to be safer than other high-risk environments such as restaurants due to the familiarity and structure of the environment. There was a routine with food as it was

constrained to breaks and lunch times, with lunch for children without FA provided by the school. This routine made children such as Elliot feel more able to be in control of keeping themselves safe:

"School is more dangerous I think for my allergies, but in a way, it's better than say a restaurant, because I know everyone and everything there, and everything is always the same, so I feel like I know what to do about my allergies better." – Elliot (10yrs)

But despite familiarity and structure, there wasn't the same level of trust at school as there was in the home. In place of parents, there were teachers who children felt were ill-informed about their allergies. There were also other children who, although knew about the child's FA, were perceived to not have the same understanding of the risks:

"The teachers know about it, but I don't know how much they really know about my allergies." – Jacob (11yrs)

"I don't think the other children really understand about food allergies and stuff, and that if I eat something that is bad that I'll have a reaction." – Sarah (8yrs)

A lack of trust in their environment and surroundings, led to increased vigilance of their surroundings. Hannah and Elliot were mindful of the risk of accidental cross contamination with food, and explained how being vigilant of their surroundings and of any foods nearby helped to minimise the risk of an allergic reaction and kept them safe:

"I have to just watch where I am and where I'm sat and things, and check that my food doesn't touch someone else's because that could make me have a reaction." – Hannah (9yrs)

"I have to look around and make sure my food doesn't mix with my friend's food and things like that, so I don't have a reaction and make sure I don't touch somebody's food by accident." – Elliot (10yrs)

Emma and Mike would ask their friends about the content of their food if they felt unsure. This gave them both the option to adapt to their situation, such as swapping seats with their friends or take extra precautions by keeping their food as separate as possible:

I: "What do you do when you're at school and see some food that you're unsure about?"
E: "I'll ask what's in the food, just to be safe and if it has something in it that could make me react, I'll swap seats with my friends so I'm a bit far away from it." – Emma (8yrs)

"I'll ask them what's in the food? And if it has nuts or something, I'll just keep my food covered and just make sure I'm not near it or coming in contact with it." – Mike (11yrs)

For Jacob and Christopher, risk was managed through avoidance of certain parts of the school where food exposure would be high, such as the school dining room. Both boys would eat separately from their friends, rather than join them in the dining hall. For Christopher, having prior experience of an allergic reaction that couldn't be prevented due to accidental ingestion of an allergen, served to reinforce his perception that dining halls were not only dangerous but also difficult to control:

"There's the lunch hall, but I don't go there because of allergies and things might have allergies in and things like that, and I don't know if I'll have allergic reaction there, so I don't eat there." – Jacob (11yrs)

"I eat in a different room than everyone else because I had a reaction once and I'm scared it'll happen again because I couldn't stop it last time." – Christopher (10yrs)

At school, children had minimal responsibility for their medication. At the time of interview, every child attended primary school, but due to health and safety policies were not allowed to carry their medication with them around the school premises. Medication was instead kept at a central location in the school, such as the school reception, or the nurse's office. Whilst this relinquished the child of any responsibility for carrying medication, children were instead found to maintain safety by ensuring that they knew where their medication was, what to do if they felt that they needed their medication, and who to ask for it when they started to feel unwell, as Eliot and Millie described below:

"They have my EpiPen and stuff in the office and at lunch, I'll always need my inhaler at lunch before I eat, so I know to go down to the office, and they'll have it there if I need it." – Elliot (10yrs)

"The teacher has my EpiPen, so I know if anything happens, if I feel like I'm having a reaction, then I ask her. And there's also one in the nurse's office which is close to the playground in case anything happens during break or lunch." – Millie (10yrs)

Millie also reflected on the future and how she would manage the transition to secondary school. She felt inexperienced in carrying her medication with her as this was either managed for her by her parents or by the school:

"It's good that my school has it but sometimes I think what will happen if I go to secondary school? I think I'd have to carry it with me all the time but what if I forget because I'm not used to it?" – Millie (10yrs)

Coping strategies in this theme largely aligned to the primary control coping construct of the CBMC (Table 4.2). Children heavily depended on their parents to cope with risk for them, both in places they considered to be safe and high-risk. Outside of the home, children relied on parents to keep them safe, particularly if food was involved. Parents were responsible for alerting others to their child's FA and ensuring that their surroundings were safe. At school however, children coped more independently by using strategies such as vigilance or making enquiries of their friends' food to minimise risk. Disengagement strategies such as avoidance were identified when risk appeared to be high and uncontrollable for the child, such as in the school canteen.

4.10.2. Theme 2: Not knowing enough about food allergy

Knowing enough about their FA could help to prevent children from taking risks with their food and health, whilst not knowing enough could lead to a greater dependence on parents for support. Every child was able to articulate what foods they were allergic to, why they had to avoid them and how to prevent an allergic reaction:

"I know if I have nuts, I can have a really bad reaction and die." – Sarah (8yrs)

"I know I should check the labels, so I go to the back of the packet and look for the writing in bold." – Elliot (10yrs)

The temptation to eat unsafe foods could be high, and children admitted to feeling tempted to eat foods that they shouldn't, particularly if it was something that they had never eaten before as Elliot described:

"Don't get me wrong, sometimes I do want to try something if I haven't had it before." – Elliot (10yrs)

But despite this temptation, no child described trying unsafe foods even when offered by friends. Exploring this further, children were scared about the consequences of eating something they shouldn't such as an adverse reaction, the possibility of a hospital attendance and even death:

"I'm scared I could die if I eat something I shouldn't, like with nuts and stuff in it." – Jack (10yrs)

When faced with the temptation of trying foods that appealed to them or that they had never tried before, children knew to check what was in the food and then refusing it if it was unsuitable:

"My friend offered me some chocolate once and I asked where it was from and what was in it because it probably had something that could make me react. She looked at it and it did, so I said no thank you." – Hannah (9yrs)

"If my friend offered something, I just say no because it might not be safe for me to eat." – Millie (10yrs)

Whilst children were knowledgeable about the foods they were allergic to, and the consequences of consuming these foods, there was variability in knowledge around reading trace-labelled products and adrenaline auto-injectors (AAI) across the group.

Younger children in the group (below the age of 10) appeared to have more difficulties in interpreting "may contain" labels. For example, Sarah found it difficult to decipher its meaning and understand whether food was safe or not for her to eat:

"If it says may contain, I don't know if that means it's safe or if I might have a reaction." – Sarah (8yrs)

Labels that clearly stated the presence of an allergen were clear and easy to understand; however, with 'may contain' labelling, younger children described going to their parents to clarify whether they were able to eat the food. This illustrated again by Sarah who describes approaching her mother for help in deciphering its meaning:

"If it says 'contains nuts' then I know I can't have it. But if it says, "may contain" on the front I get a bit confused about it and have to ask my Mum if it's ok and to read it for me." – Sarah (8yrs)

This contrasted with older children in the group who appeared to have a better understanding of what 'may contain' labels meant. As Callum explained his quote below, he knew 'may contain' labels had a purpose of warning consumers of the potential of allergens, but it did not strictly mean an allergen was present. His quote below demonstrates that he is mindful of the potential risks with trace-labelled foods:

"I know if it says may contain, it doesn't always mean it's going to have nuts or something in it. It's like a warning saying it may be in there, but it might not be. You just have to be extra careful." – Callum (11yrs)

Across the age group every child knew why they needed an AAI and why it was used; however, many did not know *how* to use it or indeed *when* to use it if it was required:

"I don't know how hard I'm meant to press it, or where it should go. And is it going to hurt if I press it really hard? That scares me because I don't know about it." – Jack (10yrs)

"I get a bit scared about when to use it if I needed to would I do it too late?" – Jasmine (9yrs)

A lack of AAI knowledge appeared to be associated with a lack of experience of using the device. None of the children interviewed had administered an AAI themselves, and those who required an AAI previously had parents administer it for them:

"I've never had to use my EpiPen before, so I don't know how to use it." – Sarah (8yrs)

Only one child could remember being taught how to use their AAI by their doctor. However, Callum felt that repeated education would be beneficial as he was unsure if his knowledge around AAI use was accurate or not:

"My doctor taught me how to use my EpiPen, we used a fake one. But it was a really long time ago now and I don't know if I'm remembering correctly like how to use it and stuff, I want, it would be better if he showed me each time I went to see him I think." – Callum (11yrs)

When faced with the possibility of needing to use an AAI, every child expressed a preference for their parents to administer their medication as parents had both the knowledge and capability that they didn't have:

"I'd rather someone else or my Mum or someone do it for me because I don't know how to do it." – Callum (11yrs)

For Jack, it wasn't just his uncertainty around how to use his medication but a shifting of responsibility for using it. As his mother already took responsibility for carrying his medication for him, he felt it was easier that his mother administered his AAI rather than do it himself, thereby using social support to cope with this:

"Mum carries it for me anyway so it's just easier if she uses it if I need it." – Jack (10yrs)

Though there could be uncertainty regarding FA and how to manage it, many children tried to enhance their knowledge, demonstrating both problem-solving and social support coping strategies. Parents were educators as well as protectors, and many children described coping by working collaboratively with their parents to learn to read labels properly. For example, parents read labels to their child to teach them, and their child read labels to them to affirm that they had learnt the skill. Working with parents could be useful to develop label reading knowledge and skills as Sarah and Mike both explained:

"So, my Mum and I would read them together in Tesco. She'd say what does it say on the pack of this packet here? And I'd read it to her and then she'd check to make sure we got it right." – Sarah(8yrs)

"I know where to find the information and understand it and stuff which is helpful for when I am older and go to secondary school and stuff." – Mike (11yrs)

Websites and social media provided a gateway for further information and was the most accessible resource particularly for the older children in the group (aged 10 and 11). Such websites could provide "tips and tricks" for children such as Elliot to use in practice:

"There's this website, I can't remember what it's called but it's for children with allergies and it has these tips and tricks on how to look after your allergy better and it tells you about your allergy and stuff and it's really good. I've used some of the stuff they've mentioned, like having a special clip holder for my EpiPen for my school bag which will make it easier for secondary school." – Elliot (10yrs)

Having internet access not only provided advice, but also quick answers to their FA questions. Using the internet was perceived to be easier than asking parents or their doctor (particularly if their appointments were spaced out) as it could provide immediate answers to questions as Jonathan explained:

J: "I like to go on the internet to look up stuff for my allergies and learn about it and stuff."
I: "What about asking your Mum, or your allergy doctor at the hospital?"
J: "It's easier to go on the internet, it's quicker because you just google it. Plus, I only see my doctor once a year so now I won't see him until next year. I can't wait that long for an answer [laughs]." – Jonathan (11yrs)

Video-sharing websites such as YouTube were seen as an excellent resource by the children to teach themselves how to use an AAI as the information was clearer and more informative. Visual aids, such as videos, were interpreted as particularly valuable over written aids when it came to providing educational information around AAI use. In contrast to information on a leaflet provided by an allergy clinic, children such as Francis felt more informed using videos as a learning tool as he could watch, learn and imitate how to use an AAI, something he felt was impossible to do through a leaflet:

"But I have been on the internet, like on YouTube to watch how to use an EpiPen which has been good because it shows you what to do. You can see where it has to go and how long to press it down for and stuff. I pretend I have my EpiPen and do it at the same time. I can't do that with a leaflet." – Francis (10yrs)

Some children discussed attending allergy "shows" which could provide helpful advice on FA management. As well as a place to gather information, allergy shows could provide useful tools that could help facilitate certain aspects of FA management that were perceived to be challenging for children. For example, Elliot described purchasing a special bag that could hold his allergy medication, reflecting on the positive impact it would have in helping him to carry his medication more easily. This bag aided Elliot to cope with his FA more independently as he was able to carry his own medication:

"I bought this bum bag from the Free From Show to hold my medication. And it's really good like, because it has a clip here and I can clip it to my bag so I can carry it easier with me." – Elliot (10yrs)

Two children described the benefits of attending allergy support groups. This was not only a place to learn more about their FA and share ideas on self-management skills to build self-confidence, but also a place for peer support from other children who were also allergic to food. Both Sarah and Elliot placed value on the information they were given by other peers, which was more meaningful to them as advice came from children just like them who understood what it was like to be allergic to food:

"Yeah, I've been to the itchy scratchy club which is a charity that we saw at the Free From Show, it's on Facebook and stuff and it's good to share like ideas with allergies and foods and stuff, or if anything happened with foods and stuff, like if there was a tiny change in a food then people would let other people know and stuff." – Elliot (10yrs)

"I went to one of those clubs for children with allergies, and it's nice because they have allergies too and they tell us how to look after it which is really helpful because they have allergies too." – Sarah (8yrs)

Coping strategies in this theme aligned with the primary control coping construct of the CBMC (Table 4.2). When children felt they didn't know enough about their FA, they depended on their parents to read labels or be in charge of administering medication. Dependence on parents was also influenced by lack of experience, particularly with using an AAI. However, there were examples of children seeking to enhance their knowledge by utilising resources such as their parents to educate them or take them to support groups or shows, or by using technology such as the internet to find answers to questions they had or as a visual aid.

4.10.3. Theme 3: How being allergic to food makes me feel, and what I do to feel better

Being allergic to food left children feeling a range of emotions such as sadness, worry, frustration and anger that they had to cope with a FA. Children expressed anger and frustration if they were the only members of the family *with* a FA, as Sarah explained below. Sarah felt that it wasn't fair that she developed a FA whilst the rest of her family were able to live their lives normally. In her quote, Sarah defines her family as normal, implying that she perhaps sees herself as not normal or abnormal due to her FA:

"Like sometimes I'm angry that it happened to me because my older brother he doesn't have a food allergy, my Mum and Dad don't have a food allergy, so I don't know why I got it and it's not fair because they get to be normal." – Sarah (8yrs)

Managing FA could be particularly challenging if children had healthy siblings, as they indirectly emphasised the restrictions FA placed on them. Observing their own restrictions could fuel negative emotions as explained by Millie who often felt frustrated that her brother was able to buy food he liked without any restrictions, while she was not able to due to her FA. This often resulted in Millie shutting herself away from her family and using distraction to take her mind off the frustration if it became too much to bear:

M: "I can see my big brother going out to the shops and he can go get anything he likes and doesn't have to worry but I can't do stuff like that, it isn't fair and it really annoys me so much."
I: "What do you do when you feel like that? Do you do anything to –"
M: "I go to my room and maybe read a book or watch something on YouTube to take my mind off things." – Millie (10yrs)

Children often reflected on the restrictions on their everyday activities and how this made them feel. For example, Jasmine spoke about the restrictions placed on her being able to attend social functions like birthday parties which she felt wasn't possible with her FA. Exploring this further, Jasmine explained how she would often find something nice to do with her Mum instead. Distraction in this way helped her to take her mind off the sadness:

I: "How does that make you feel not being able to go to birthday parties?"
J: "Uhmm a bit sad, like I feel sad."
I: "Do you do anything to cheer yourself up when you feel like that?"
J: "My Mum and I will go out and do something nice for the day which makes me happy." – Jasmine (9yrs)

Every child I interviewed, described experiencing worry or anxiety over their FA and whether they would experience an allergic reaction. Living with this uncertainty caused Millie and Hannah to worry about their FA on a regular basis:

"I do worry about it a lot; I worry if it'll have an allergic reaction today. You just never know." – Millie (10yrs)

"Because it can happen anytime it does worry me, it does yeah, I do worry about it quite a lot." – Hannah (9yrs)

As identified in Theme 1, certain locations were perceived as high-risk, and being in these locations could also trigger worry and anxiety, especially if an allergic reaction had occurred there. For Christopher, his school was a high-risk location and one where an allergic reaction occurred. This led to Christopher experiencing daily worries that could be all-consuming. This led to hypervigilance and checking behaviours to cope, such as always checking whether he was showing signs of an allergic reaction, which although intended to alleviate anxiety, may have also had a role in exacerbating it:

"I had a reaction at school which was scary, and so, so it's so I worry about having a reaction every day now when I'm at school. Like when I'm at school, I'm always checking or asking if my eyes are swelling because that's the first sign of a reaction, so I know, so I'm always worried about whether my eyes are going swollen or not and I go to the bathroom to check." – Christopher (10yrs)

Parents had an important role in helping to manage their child's emotions, and every child described approaching their parents when they felt worried or distressed about their FA. Parents could provide reassurance and advice which could help to alleviate the intensity of these feelings. This form of reassurance was crucial in high-risk locations such as restaurants, which could cause increased levels of worry and anxiety over the possibility of an allergic reaction. In addition to the practical role parents had (as identified in Theme 1 to help cope with risk), parents also had an additional role in keeping their child calm and reassuring them that they would be safe even in high risk/unsafe locations. As Jonathan explained, the reassurances that parents gave could make him feel safer in an environment that triggered anxiety and worry:

"Yeah, I speak to my Mum like, I speak to my Mum and say to her things like I'm quite worried about my food allergy, and she will always make me feel better and I don't feel like anything bad will happen." – Jonathan (11yrs)

Two further sources of emotional support were identified; the support of older siblings who also had FA, and the support of healthcare professionals. Siblings with FA were both an important and unique source of support as they fully understood the challenges of coping with a FA and how it made them feel. Two children described the importance and value of having an older, food-allergic sibling to approach when their condition was causing them to feel upset. Not only were these siblings able to provide emotional support such as reassurance, they also provided an outlet for children to be able to discuss their feelings about their FA with someone who could understand, as Jasmine and Emma explained:

"Yeah because he has a food allergy too, it's not the same as mine but he understands how I feel because he has one too and if I'm feeling worried about something, he will say its ok and I'll be ok." – Jasmine (9yrs)

E: "Being able to talk to talk to my brother is nice because he understands it because he has allergies to. I don't think I'd be able to talk to people about my food allergy if I didn't have him."
I: "Why's that?"
E: "Because he understands what it's like to have a food allergy and no one else does." – Emma (8yrs)

Jasmine further explained how her brother helped her with some of the practicalities of FA management, such as label reading and explaining to her if food was suitable to eat if it was labelled 'may contain'.

The emotional support sought from HCP came from counsellors via the school pastoral system. Having access to counsellors gave two children an opportunity to not only discuss their feelings and worries

related to their FA, but to also learn strategies to help cope with these feelings when they emerged, as Elliot and Christopher described:

> *"Yeah, I used to speak to this guy who would come to our school, like every Thursday. He would help people with all sorts of things, and I would speak to him about my allergy and he taught me how to deal with my worries about my allergy and stuff." – Elliot (10yrs)*

> *"At school, there's this room called The Zone where there's these people that work there and they talk to you and make you feel better so they'd make me feel better about my food allergy, I could just talk to them about it and they would help me not to worry so much about it after I'd had a reaction." – Christopher (10yrs)*

A salient point identified in the discussions with both Christopher and Elliot was the way support was sought. Both boys approached counsellors independently, and not due to a referral or suggestion made by their parents or teachers. This not only demonstrates that children of this age group actively seek professional support to help them cope with their feelings, but it also shows that children were able to make independent decisions to discuss their feelings with a professional and take control over how they coped with the emotional impact of their FA:

> *"The school had this person we can go talk to. So, like when he came round, I asked him 'could we talk?' because I thought it would be a good idea. So, no one made me go and speak to him, I went up and asked and we went to this room in the school which is called the comfy corner which has all these comfy sofas and it has one of them egg seats, so it's got one of them, it's a really nice room." – Elliot (10yrs)*

Sometimes physical avoidance would be the only way to manage anxiety. Birthday parties could be a precarious social situation as the risk was high, coupled with a reduced parental presence that was associated with trust and safety. Jasmine found it difficult to trust that she would be safe, even if she was able to take her own food with her. The only way she could assure her safety and reduce her worry was by not attending:

> *J: "I don't go to birthday parties because in case the food isn't safe and there'll be lots of other children there and it could dangerous."*
> *I: "So do you prefer to not go to birthday parties because you're worried about your food allergy?"*
> *J: "Yeah it scares me, if I don't go I know I won't have a reaction." – Jasmine (9yrs)*

Declining invites to birthday parties alleviated one emotion – anxiety but resulted in another - sadness. Despite how Jasmine felt about not being able to attend a birthday party, the worries she expressed over attending them was too great to manage in any other way. Knowing that she would feel sad became a part of her decision-making process:

> *"Not being able to go makes me feel sad, but uhmm…I don't want to go to them because they scare me about reaction. I know I'll be sad when I say I can't go but I worry about having a reaction, so I just have to deal with it." – Jasmine (9yrs)*

Ruminating about the FA and its limitations could also exacerbate feelings of sadness. Using distraction, such as engaging in a hobby or thinking about something unrelated to the FA, distracted the child from thinking about their FA, as Francis explains:

"I'd just distract myself and not really think about it and think about something else instead like football or my games or something." – Francis (10yrs)

Distraction methods allowed children to temporarily "forget" about being allergic to food, which could provide some relief. However, Francis reflected on its ineffectiveness as a coping strategy as relief was only temporary. Francis' description of the constant physical presence of being allergic to food which would never disappear, no matter how much he would try to forget about it, was quite insightful:

"Even if I think about something else, like, I don't know, football, I'm still, I've still got a food allergy. It doesn't go away, and thinking about something else it uhmm, it doesn't last forever does it?" – Francis (10yrs)

The use of positive thinking or cognitive reappraisal could help change how children felt about their FA. For example, Hannah discussed finding some positive features despite being allergic to food. Though she reflected on her restrictions, Hannah felt that it wasn't "all that bad" when she focussed on her favourite foods that she could eat and what she was able to do, rather than on what she wasn't able to eat:

"So, I sometimes think it's not all that bad when I can eat some of my favourite foods and still do things I like." – Hannah (9yrs)

Children also made use of downward social comparisons and FA hierarchies (where one FA is perceived to be better or worse than another). Believing that things could be worse, that they could have more severe afflictions than being allergic to food or have a greater number of foods to which they were allergic to, helped children to view their condition more positively, as Francis illustrated below:

"I could be allergic to so much more stuff and I'm not so it's not that bad really. I think if maybe I was allergic to more stuff, I'd get upset about it, so whenever I do get down about it, I just think, it could be worse." – Francis (10yrs)

Some children used hierarchies by making comparisons with foods that they perceived to be more limiting. One child perceived her allergy to nuts to be easier to manage as she felt a nut allergy was better known to others than an allergy to dairy or meat. Despite finding her allergy frustrating, Millie felt that she was in a fortunate position having a well-known allergy, and reflected on how anxious she would have felt eating out in public had she had been diagnosed with an allergy to different foods:

"I think it's better than an allergy to something else, I don't know, like uhmm, meat or something because everyone knows about peanut allergies, so I think I'd be worried all the time if I was allergic to something else if we went out to eat." – Millie (10yrs)

Francis believed that a dairy allergy would be far more restricting than his peanut allergy as his favourite foods were dairy based:

"I really like ice creams and stuff, so if I had a milk allergy or something, I couldn't eat that stuff, so I think that would be worse than being allergic to peanuts" – Francis (10yrs)

All three factors of the CBMC were identified in this theme (Table 4.2). Emotional social support (primary control) helped to alleviate feelings of both sadness and anxiety or worry, particularly in high-risk situations. Parents were an important source of emotional support but having another person close to them with a FA, such as siblings, provided an additional source of support. Disengagement coping strategies was seen as only a temporary solution to some, whilst others found that at the cost of alleviating worries there was increased sadness at missing out on social activities. Secondary control-coping strategies such as positive thinking and downward social comparisons were used when children felt low in mood. Rather than dwelling on the negatives and limitations of their allergy, focussing on the positives or making comparisons with others perceived to be in a worse situation than their own helped to alleviate these feelings.

4.10.4. Theme 4: "I have a food allergy, but I still think I'm like my friends."

Although not a visible condition, the physical characteristics of FA management such as carrying medication and actively avoiding certain foods, made children feel different from their healthy friends and peers. Feeling different because of the FA could have an impact on the strategy's children used to cope with the FA.

Identity was important as children didn't want to appear unusual to their friends but felt that they were due to their FA. The experience of feeling different was especially important at school when surrounded by healthy friends and peers:

"No one else has it and no one else has to carry their medicine on them like I do, so it makes me feel different from everyone." – Jacob (11yrs)

Many children expressed trepidation regarding how their friends would perceive them because of their allergy. For example, Elliot had concerns over whether his friends would think differently of him because of his medication, whilst Callum was particularly apprehensive that his friends would perceive him to be fragile due to his condition and would isolate him from their friendship group:

"I don't want them to think differently about me, and I worry that my medicine makes me looks different and stuff." – Elliot (10yrs)

"I don't want my friends to think, 'Oh he's always ill' or something, and then leave me out of things because they think I can't do it." – Callum (11yrs)

Providing own lunches to school further enhanced the perception of difference felt between the child and their healthy friends and peers. This was illustrated by Sarah who described how everyone at school could eat school prepared lunches, whilst she had to supply her own. Wanting to be able to eat in the same way as her friends, emphasised how different she felt from them:

S: "Everyone else is eating school lunches, and I have to bring my own lunch in from home."
I: "Is that something that you don't really like doing?"
S: "Not really, I want to be able to eat the same as them but I can't, I have to have my own food." – Sarah (8yrs)

The desire to appear more like their friends and less like a child with FA led to children minimising the presence of their condition. For example, Elliot felt that his medication defined his difference from his healthy friends and peers and hid his medication from them. By hiding this, he was able to convey an image of normality:

E: "I don't like to show my allergies like I don't like to show that I have it if you know what I mean? Because I have all these allergy medicines and stuff and I don't want to be different, but it's making me different."
I: Why do you not like showing that you have a food allergy?"
E: "I don't like showing it because like, so I used to say 'Oh it's just my lunch in here', but like yeah don't like showing it, so I try and hide it so I just look normal like." – Elliot (10yrs)

As well as physically concealing his medication, Elliot also described creating excuses to refuse food he was unable to eat, by drawing the attention away from his FA. Saying he wasn't hungry, rather than saying he was unable to eat the food due to his FA, was preferable as it conveyed normality. Elliot felt that every child could understand not being hungry, however, not every child could understand being allergic to food:

E: "So, say my friends offered me something like, I don't know, peanuts or something and I'd just say I wasn't hungry rather than oh I'm allergic to it."
I: "And how come you'd rather say that than tell them it's because of your allergies?
E: "Because I look more normal saying I'm not hungry than saying 'Oh it's my allergies', everyone knows what it's like to be hungry but only I know what it's like having allergies." – Elliot (10yrs)

Children could also minimise the presence of FA by avoiding conversations with their friends and peers about their condition. Avoiding these conversations not only had a purpose of drawing attention away from the condition, but could also give the appearance that being allergic to food didn't affect them, as Jacob describes below:

"I don't really want to talk about my allergies with my friend's because I don't want the attention for them to think I'm like always ill or something. If I don't mention it, then it makes it look like I'm ok and my food allergy isn't a big deal" – Jacob (11yrs)

However, this had a secondary effect as by avoiding conversations of and minimising the presence of a FA, children were restricting their access to support from friends, as Jasmine explained:

"Because I don't really talk to my friends about it, I don't have them to speak to if I'm worried about something like maybe we're having a school trip and I'm worried about my allergies and I can't say to them that I'm feeling worried." – Jasmine (9yrs)

Similar to the previous theme, children were found to use positive thinking and cognitive reinterpretation to normalise their FA and their identity. Sarah spoke of trying to find positivity in being different and believed her FA conveyed her uniqueness and shaped who she had become:

"S: Well I just know that uhmm, I just think that uhmm that if I didn't have food allergies then I might be different, a different person."
I: "So you like who you have become because of your allergies?"
S: "Yeah because it's made me who I am." – Sarah (8yrs)

Sarah's quote above demonstrates that even at a young age, mature and reflective thinking can help cope with having a FA.

Children were found to make downward social comparisons, similar to those made in the previous theme. An illness hierarchy, rather than a FA hierarchy, was also incorporated within these social comparisons by comparing FA against other chronic conditions such as diabetes or eczema. This was adopted by both Jacob and Elliot, who both struggled with feeling different from their friends and so minimised their allergy. Both boys felt that in comparison to diabetes and eczema, having a FA made them appear normal as this was a hidden condition with no outward symptoms unless experiencing an allergic reaction. Normality was based on the management or physical symptoms of other illness, such as the use of insulin injection for diabetes or the obvious rashes on the skin that children with eczema may have to deal with:

J: "Because with my allergies, it's better because I don't have to uhmm have to inject myself like if I had diabetes."
I: "Do you think that having a food allergy is better than diabetes?"
J: "I think so because you'd always have to inject yourself and everyone would see, I think having a food allergy makes me look normal like everyone else because my EpiPen is just in my bag and no one has to see it." – Jacob (11yrs)

"Someone in the class above me had really bad eczema and you could see it on her arms and legs so I think I'm ok because you can't see my allergies really and no one stares." – Elliot (10yrs)

Another way of coping with feeling different was demonstrated by some children creating their own version of foods to replace those that they could not eat. By creating their own foods, both Jonathan and Mike were able to regain some normality by creating foods that retained some similarity to the foods they could not eat. Additionally, they described not feeling left out by making these foods, which highlighted the importance of the social experience of not only eating, but eating foods that were similar to their healthy friends and peers:

M: "I make my own ice lollies instead because I can't have dairy so I can't have ice creams."
I: "That's got to be nice, to be able to still have something similar?"
M: "Yeah because if my friends come over, they can have something like an ice cream, and I won't feel left out or different because I can have my ice lolly." – Mike (11yrs)

"I know how to make pasta sauce. So, at school when we were cooking I made my own

pasta sauce for me because they were going to do this cheesy pasta and I can't have dairy, so I made my own pasta sauce because otherwise, I would've had plain pasta so I could have pasta as well with sauce, even if it was a different sauce from my friends."
– Jonathan (11yrs)

Coping strategies in this theme also aligned with all three components of the CBMC (Table 4.2). Disengagement coping strategies that hid or minimised the presence of their FA was used in an attempt to appear more like their friends, even if it could put them at risk of having an allergic reaction or inhibited the use of their friends as a source of support. Using secondary control coping strategies helped children to view their self-identity more positively, viewing themselves as no different from their friends. Primary control coping strategies, such as creating safe foods to replace those that they could not eat, helped children to feel normal.

4.11. Discussion

This qualitative study provides insight into the coping strategies used by children with FA. Four themes were identified which not only identified coping strategies but provides further understanding of the context in which they are used: 'Staying safe in high and low-risk places', 'Not knowing enough about food allergy', 'How being allergic to food makes me feel'; 'I have a food allergy, but I still think I'm like my friends'. This study further adds to the FA literature where children of this age had been underrepresented, as identified in the systematic review of Chapter 3. It is unique in its specific approach towards understanding coping strategies within the context of a CBMC, a model that has not been used in FA research.

4.11.1. Main findings

Children were found to use a range of primary-control, secondary control and disengagement coping strategies depending on the context that they were used in. The results of this study support the findings of previous literature regarding the behaviours used by children. Using the CBMC enabled me to map these behaviours onto particular coping strategies (Table 4.2).

Children understood 'risk' as 'high risk' or as 'low risk', parallel to the findings of DunnGalvin et al. (2009) and Fenton et al. (2011). An interesting finding were the ways in which children coped in places they deemed to be low risk. At home, rather than using primary-control coping strategies such as being vigilant or avoiding allergens to minimise risk, children were instead coping indirectly through a reliance on their parents to provide a safe environment and home was always perceived as safe, a sentiment that has been identified before (DunnGalvin et al., 2018).

As parents had full control over the home, this appeared to relinquish the need to be aware of their surroundings. In contrast, at a friend's home, the perception of 'low-risk' appeared to change. Children appeared to use risk calculation, a phenomenon identified in adolescents with FA (see Akeson et al., 2007; Mackenzie et al., 2009; Sommer et al., 2014), when going to their friends' home. Primary control

coping strategies would be used if there was a chance of an allergic reaction occurring, with children taking their medication with them. Disengagement coping was identified if children felt that the risk of a reaction was very unlikely, choosing to leave medication at home.

Table 4.2: CBMC constructs attributed to each theme

Theme	Primary-control coping	Secondary-control coping	Disengagement coping
Theme 1	• Using social support (parents) • Vigilance of surroundings • Enquiring about food content. • Carrying medication • Informing others of their FA	• Not identified in this theme	• Avoidance (restaurants, birthday parties, school canteens)
Theme 2	• Using social support (parents) • Using the internet to seek further information • Attending FA support groups. • Visiting allergy "roadshows"	• Not identified in this theme	• Not identified in this theme
Theme 3	• Using social support (parents, siblings, healthcare professionals)	• Positive reinterpretation • Downward social comparison • Food allergy hierarchy • Distraction	• Avoidance
Theme 4	• Creating alternative foods	• Positive reinterpretation • Downward social comparisons • Illness hierarchy between other conditions	• Minimising/hiding the presence of FA

These findings support previous research where familiarity has influenced a child's decision to carry medication with them (DunnGalvin et al., 2009), and has also been identified in adolescent literature (Gallagher et al., 2011; Macadam et al., 2012; Mackenzie et al., 2009; Monks et al., 2010). Though accidental exposure to allergens can happen in the home (Sicherer et al., 2001) this was not a finding in the present study. This could partly explain the children's perception of safety. Additionally, the parents of the children in this study may be particularly protective of their home environment as many children expressed that their home had a strict allergen-free policy that all family members had to adhere to.

There was a variation between the types of primary control coping strategies used in high-risk locations. In restaurants, there was a greater dependence on parents as a coping strategy, whilst at school, there was more independent use of primary control coping such as being vigilant or enquiring about food content. The dependence on parents for social support in children has been identified in FA research and general coping literature, particularly in high-risk locations such as restaurants (DunnGalvin et al., 2009;

DunnGalvin et al., 2018; Skinner & Zimmer-Gembeck, 2007). An explanation for this could lie in the perception of controllability, a key feature of the CBMC that plays a role in the coping strategy used (Compas et al., 2012). High-risk environments such as restaurants were viewed as unpredictable, an opinion that has been identified before (DunnGalvin et al., 2009), whilst school could have some element of structure and routine. It is possible that children feel unable to exert control over their FA in environments such as restaurants, thus relying on parents to help them cope with their FA. Controllability could therefore influence support seeking from parents, as has been identified by Skinner and Zimmer-Gembeck (2007).

Alternatively, it could be argued that at school, the absence of parental presence gives children little choice but to manage their FA on their own and could facilitate use of primary control coping strategies independently. However, the issue of controllability remains crucial, as some children who felt that school was too unpredictable and unsafe were found to use disengagement coping strategies instead, such as avoiding certain parts of the school. It could be possible that such disengagement coping strategies are being used as a substitute for seeking support from parents.

Knowledge of FA was found to play an important role in the coping strategies used to minimise risk associated with FA, particularly with regards to use of medication and understanding the consequences of taking risks with their FA. Children understood what they were allergic to and knew the consequences of consuming an allergen and used appropriate primary-control coping strategies to minimise their risk such as by checking food labels and packaging and avoiding allergens. This contradicts the findings of recent research that suggested school-aged children could lack the cognitive capacity to appreciate the consequences of disease (Sonney, Insel, Segrin, Gerald & Moore, 2017). Though this research was based upon medication adherence in children with asthma aged 6-11 years old, the present study does suggest that school-aged children (who are of the age range of the study by Sonney et al., 2017) can have the capacity to appreciate the consequences associated with their condition and use coping strategies to minimise risk.

Knowledge regarding AAI's varied, and children said they would seek parental support if they needed to use their AAI as they felt they didn't know enough about how or when to use it. Issues in AAI knowledge isn't atypical as identified in adolescents by Gallagher et al. (2011), and the way children are taught to use their AAI may contribute to deficiency in knowledge, as has been identified before in adolescents by Monks et al. (2010). It is possible that AAI education is not directed at children enough, as advice may be given to parents instead. It is also likely that parental knowledge may be deficient regarding AAI use and are therefore unable to pass on that information to their children. A randomised controlled trial of mothers showed almost half of the sample forgot how to use an AAI six weeks after training (Umasunthar, Procktor, Hodes, Smith, Gore et al., 2015). This may be due to issues such as an infrequency or quality in AAI training or poor follow-up appointments (Blyth & Sundrum, 2002; Gold & Sainsbury, 2000). Repeated education is important for youth with chronic illness (Taddeo et al., 2008),

and may be required during childhood in order to grasp and understand how and when to use their AAI, and to facilitate more independent use of primary control coping strategies when it comes to using their medication.

A novel finding in this study was the use of the Internet to seek information and learn more about their FA, which has not been previously identified with this age group and demonstrates the use of primary - control coping in this age group through problem solving to learn more about their condition. This is similar to findings of a previous study investigating adolescents with asthma who also used the Internet for similar purposes (Rhee, Wyatt & Wenzel, 2006). The finding in the present study may have been facilitated by changing technology, including the levels and types of accessibility that children in 2018 may have compared to studies conducted in previous years, where Internet use has been largely identified in adolescents. Nevertheless, this increased access to technology has appeared to promote the development and use of problem-solving strategies in creative and independent ways when children want answers to their FA questions. However, caution may be needed as we do not know what sites or social media children may be using, and they may not know whether these sites have trustworthy information about FA.

The use of support groups was also identified as a resource for further information but also that of peer support. The benefits of support groups have been identified in adult FA literature (Coulson & Knibb, 2007), and research involving adolescents with FA aged 13-19 years old (Jones et al., 2015) and it appeared that similar benefits were also felt by children in this study, as meeting other children with FA had both educational and empathic benefits as well. As previous research has identified that children can have difficulty sharing their FA with particular friends or peers (DunnGalvin et al., 2009), peer support that is coupled with education can be an important source of knowledge and support that can also facilitate the development of appropriate coping strategies to manage FA. Moreover, peer support that is coupled with education has been identified as a need by children with allergies (Stewart, Masuda, Letorneau, Anderson & McGhan, 2011).

The emotional burden and psychosocial issues of FA in children is well documented in research (Cummings, Knibb, King & Lucas, 2010; Bollinger et al., 2006; DunnGalvin et al., 2009; LeBovidge et al., 2009). Children in the present study expressed feelings of distress such as anxiety and depression which has been identified before. Like previous research (Cummings et al., 2010; DunnGalvin et al., 2009), certain locations could be perceived as dangerous, and could trigger anxiety in children. Corroborating the findings of DunnGalvin et al. (2009), disengagement coping strategies such as avoidance were identified which saw children in this study avoid social situations that caused anxiety. The use of disengagement coping strategies may have been associated with the perception of controllability. Social situations such as birthday parties are perceived as unpredictable and even life threatening (Cummings et al., 2010), and it is possible that children find it difficult to stay in control of their FA, leading to the use of disengagement coping strategies.

Previous research using the CBMC has identified that the use of disengagement coping strategies can lead to symptoms of anxiety and depression across different chronic illnesses, such as chronic pain and cancer (Compas et al., 2006; Frank, Blount & Brown, 1997; Shirkey, Smith & Walker. 2011;Walker, Garber, Smith & Claar. 2007). However, it is possible that existing feelings such as anxiety and depression can influence the use of disengagement coping strategies such as avoidance, as has been highlighted before by DunnGalvin et al., (2009).

Whilst parents had an important role in providing emotional support, a role also identified by Fenton et al. (2011), the role siblings with FA played was an interesting finding from the present study. Having others with the same condition can be positive for children with FA (Avery et al., 2003) and the role that siblings play can be particularly special as they appear to provide both practical advice and emotional support as they understand the experiences of their younger siblings.

Emotional support from healthcare professionals was also identified and found to help children to develop adaptive coping strategies to manage their emotions. What was particularly unique of the children who sought professional support, was their independent decision making to seek such support. This demonstrates that children have insight into the way their FA makes them feel and want to be able to cope with these feelings. As this was only discussed by two of the children interviewed, it is difficult to determine whether other children had sought similar support, or if they had access to such support at their schools.

Identity was an important topic for children as they did not want to appear different from their friends. Concerns over how others may perceive their condition has been identified in previous research of children with FA (DunnGalvin et al., 2009) and children in this study had similar worries. Children did not wish to share their FA concerns with friends, nor draw their friends' attention to their FA. Disengagement coping strategies to minimise or hide the presence of FA were used, which has been identified before by DunnGalvin et al. (2009). To some extent, findings over disclosure corroborates those of DunnGalvin et al. (2009) who identified that children aged 9-11 would only share their FA with 'best friends'. Children in the present study did not describe sharing their FA openly with their 'best friends', making it difficult to make a close comparison. However, it is reflective of a point in childhood where self-identity with FA can become an unwanted focal point and can affect what children with FA share and how they cope when they choose not to share.

Some children demonstrated a creative solution to FA issues by cooking alternative foods to eat, which could be viewed as a form of primary control coping through problem-solving. Not only did this provide safe foods to eat, this could help to apply normality to a focal part of the condition that is most affected – food. Sourcing alternative, safe foods has been identified before in adolescents (Mackenzie et al., 2010); however, creating own foods appears to be a novel finding for this age group. Using problem solving in this age group has been identified in previous research with age-related increases in the use

of such strategies in mid-childhood as well as early, middle and late adolescence (Skinner & Zimmer-Gembeck, 2007).

The use of secondary control coping strategies was identified in both themes 3 and 4 of this study, was another notable finding in this study for two key reasons. Firstly, strategies such as downward social comparison, positive reinterpretation and the use of an FA 'hierarchy' have been mainly identified in adolescents with FA rather than younger children (Fenton et al., 2011; Macadam et al, 2012; Mackenzie et al., 2009; Marklund et al., 2007). These strategies have not been reported in children with FA in the age group of the current study, although they have been found in children with other conditions such as cystic fibrosis as a means of coping that allows children to evaluate their health status in comparison to others (Ernst, Johnson & Stark. 2010; Pfeffer, Pfeffer & Hodson. 2003). Secondly, the finding that young children with FA use secondary control coping strategies contrasts with early research that suggested that adolescents used secondary control coping strategies more than children due to the cognitive resources needed to employ such strategies (Weisz, McCabe & Denning. 1994). More recent work has failed to identify developmental differences in coping with chronic illness (Campbell, Scaduto, Van Slyke, Niarhos, Whitlock et al., 2009; Miller et al., 2009), and so the results of the present study add to the literature of coping in chronic illness with children and demonstrates that children use secondary-control coping strategies similar to adolescents, and such coping strategies may develop during childhood.

4.12. Strengths and limitations

This study has specifically explored the coping strategies of children aged 8 to 11 years with FA, an age group that has been underrepresented in the FA literature. Strengths lie in the qualitative nature of the research which has allowed an in-depth exploration of how children cope with their FA, and what influences their coping strategies. This study has included children below the age of 11, which was a point of further study in the systematic review of Chapter 3. Children were recruited from across the UK, and not confined to one geographical area which was helped by the way the study was advertised. The application of a CBMC also adds to the strength of this study. Whilst this model of coping has not yet been applied to FA before, the coping strategies identified in this study mapped well to the sophisticated constructs of the model and supports the theoretical basis of this model.

However, there are limitations to the study. Firstly, the majority of interviews were conducted over Skype, rather than face to face. Although this method of interviewing helped to ease the logistics of interviewing children in different parts of the country, one must reflect on the possible potential bias this method of interviewing may have been introduced. Although I was able to see the participant over Skype, it is possible that I missed elements of body language that may have alluded to a different answer to that which the child gave me. Whilst parents did not participate in the Skype interviews with children, there may have been an awareness that parents were nearby, and possibly able to hear the interview

which may have influenced the answers given. This can also apply to children who were interviewed at home.

Being interviewed at University, although a neutral setting, may not have been a comfortable location for children to be interviewed at in comparison to home. Having the familiarity of their home may have made the interview process easier for children, and may have elicited conversations that may not have been captured when being interviewed at the University. Furthermore, children who were interviewed at home, whether this was face to face or over Skype, had opportunities to show me items that they use to cope with their FA, which would not have been possible for children to being interviewed at the University. Therefore, there is some element of bias or how the conversation was able to be directed depending on the setting of the interview.

There are also limitations regarding this sample. More boys than girls participated in the study, and no boys were aged below 10; therefore, it is difficult to understand how younger boys coped with their FA. In addition to this, the majority of children were aged 10 and 11 years old, and it could be argued that we are still missing data from children below this age. Further investigation that involves younger children could help improve the understanding of their coping strategies, and whether there are any differences with children aged below 10 and 11 years old. Limitations also lie in how representative this sample is of children with FA more broadly. Firstly, the data is drawn from a majority White-British sample, with only one British-Asian participant, and thus the perspectives of children with FA from different cultures and ethnicities are not well represented. Secondly, the majority of children were diagnosed with multiple FA, with only one child being diagnosed with a single FA. It is important to reflect on this as conclusions cannot be drawn about children who are coping with a single FA only and thus the data may be biased to capture the coping strategies and experiences associated with multiple FA. Additionally, most children interviewed were allergic to peanuts and other types of nuts, and it is possible that this may have also biased the data obtained and conclusions drawn regarding the coping strategies identified may be more associated with peanut or nuts allergy. These factors will affect the development of the coping scale as the data is biased towards children with multiple FA, and more skewed towards those with peanut and nut allergy. Future research could investigate in more depth whether different sub-sets of FA use more or less of a particular coping strategy. This could help to understand the needs and experiences of those who are allergic to other types of food, and how they cope.

The children who took part in this study are generally coping well and may have been encouraged by their parents to participate in this study because of this. Therefore, this study is lacking in qualitative data from children who are not coping well and are struggling with their FA, or who are poorly supported by their parents and could be coping differently. Again, this will affect the development of the coping scale as the data used to inform the development will be biased towards children coping well with their FA. However, it is possible that children may not have felt comfortable to discuss if things were

challenging for them and how they were coping, and may have wanted to give the impression that they were doing things 'right' rather than 'wrong'. It would be interesting to know about children who are struggling to cope with their FA, and understand their reasoning and experiences behind this.

It is also important to note that it is unknown how many information packs about this study were distributed by the allergy clinics in Birmingham, with only three participants being recruited from these sites. Despite these limitations, this study has provided insight into the coping strategies of children with FA, and an understanding of their experiences of being allergic to food and what shapes the use of particular coping strategies.

4.13. Conclusion

This study has identified that children with FA use a range of primary-control, secondary-control and disengagement coping strategies. The strategies used do not greatly differ from strategies used by adolescents as identified in the systematic review of Chapter 3; however, there is a greater emphasis and dependence on parents for support which is in keeping with the findings of previous FA and coping literature. Parents have a pivotal role in how children cope with their FA. As detailed in the thematic map (Figure 4.1), social support, particularly from parents, that is both instrumental and emotional is featured frequently. This is developmentally appropriate, given that children in this empirical study spent a great deal of time with their parents and reflects previous research into children with FA (DunnGalvin et al. 2009). Whilst social support is a key coping strategy in this age group, there is evidence of children coping with their FA independently, whether this is practically, such as carrying their AAI or being vigilant of their surroundings, or through enhancing their own self-efficacy in being able to cope, such as seeking more information. The use of disengagement coping appears limited in this age group as detailed by the thematic map (Figure 4.1) and Table 4.2. This could be due to the use of support (for example, through parents) in such situations, for example, outside of the home, that would otherwise be difficult to cope with independently. However, disengagement coping by avoidance of social situations, such as birthday parties, may be heavily influenced by parents and their own anxieties surrounding their child's illness, and this may further influence children to become fearful of and avoid social situations as they grow older (DunnGalvin & Hourihane, 2009; Fox et al. 2005; Skinner & Zimmer-Gembeck, 2007).

Further research is needed to explore the coping strategies in children who struggle more with their FA, as children in this study appeared to largely cope well and have a positive perspective of their allergy. Additionally, with the majority of participants diagnosed with multiple FA, with a skew towards peanut and nut allergy, research should explore whether coping strategies differ across other types of FA. Finally, further exploration into the role's parents have in shaping these perspectives would also be useful, as it is possible that parents may have a role in the strategies used, particularly secondary control coping strategies where downward social comparisons and positive reinterpretations are made.

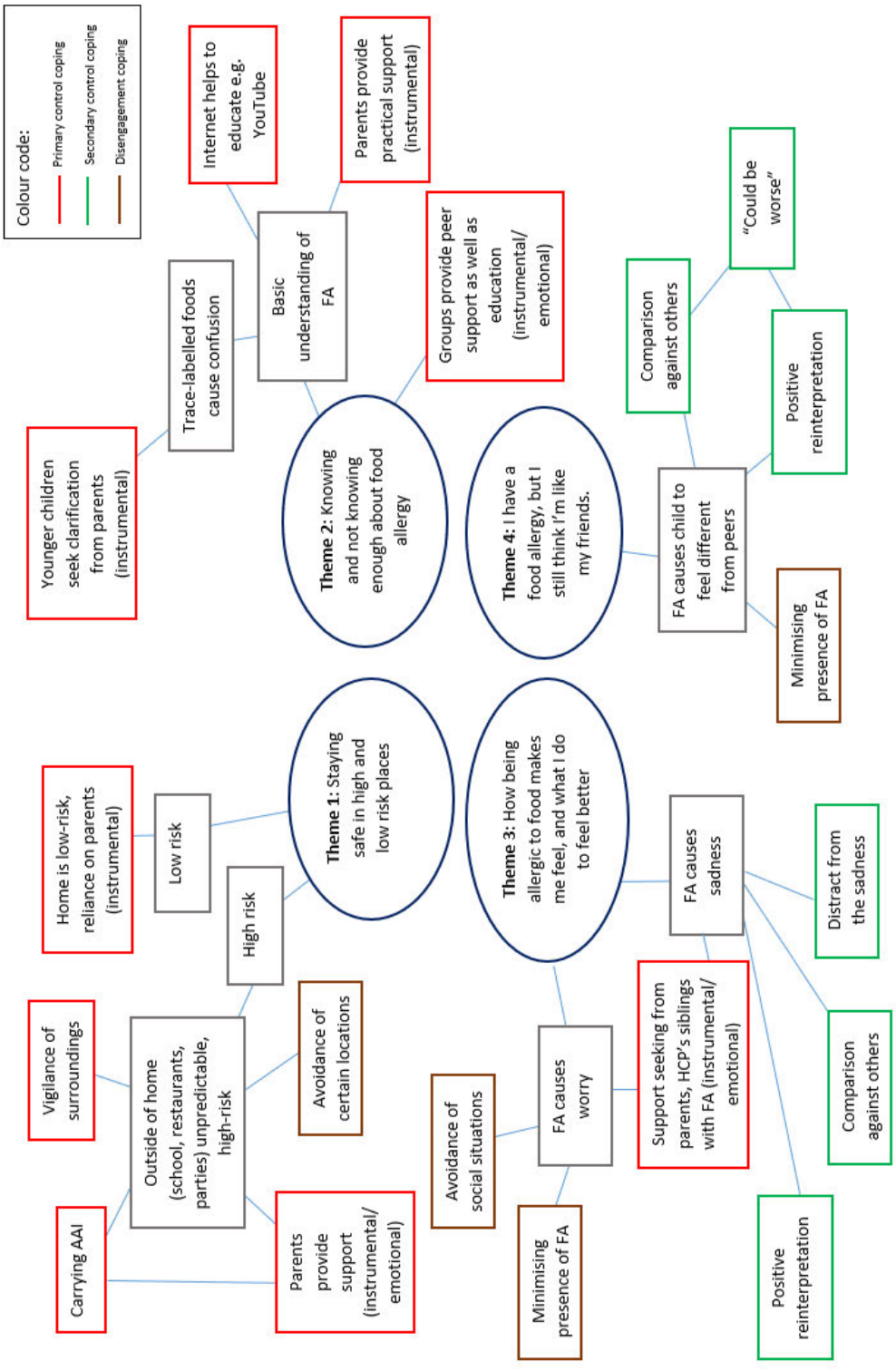

Figure 4.1: Thematic map of children's coping strategies using the CBMC

CHAPTER 5 "I don't want to appear like I'm different." A thematic analysis of the experiences and coping strategies of adolescents aged 12-16 years old with food allergy

5.1. Overview

This chapter outlines the findings from a qualitative research study conducted with adolescents aged 12-16 years old with food allergy (FA) diagnosis. As previously described in Chapter4, this age range was chosen as adolescents aged 12-16 years old had different experiences and faced different issues to children aged 8-11 years old (see Chapter 2, section 2.6.2, for the rationale behind the analysis of this age group). The aim of this chapter was to explore how adolescents coped with their FA and understand the context with which these strategies were identified and used. Like the previous chapter, this study was underpinned by the CBMC (Compas et al., 2001), which helped to categorise coping behaviours. Full details about the methodology used are described in Chapter 2.

5.2. Background

Coping with a chronic illness requires resources and strategies (Atkin & Ahmad, 2001) however, adolescence is associated with a period of "rapid physical, psychological, emotional and social development" (Taylor, Gibson & Franck, 2008. pg. 3083), which, along with increased risk-taking and reduced parental involvement, can create challenges when managing a chronic condition (Rolison & Scherman, 2002; Sampson et al., 2006). Young people with chronic illnesses experience the same developmental issues as healthy young people but have the additional challenge that their chronic illness can disrupt their development as they strive to adapt their lifestyles to accommodate their condition (Rhee, Wenzel & Steeves, 2007; Taylor, Gibson & Franck. 2008).

Adolescents with chronic illnesses, including FA, can be expected to assume "greater autonomy and responsibility" towards self-management as they transition towards adulthood (Warren et al., 2017). However, social changes such as a reduction in parental monitoring and an increase in independent socialising with friends, can be a moderator for risky behaviour. For example, reduction in parental monitoring has been associated with a decline in illness control across a range of paediatric conditions such as Type 1 diabetes (Wasserman, Anderson & Schwartz, 2017). Studies of adolescents and young adults with FA (Warren et al., 2017; Greenhawt, Singer & Baptist. 2009; Sampson et al. 2006; Monks et al., 2010) have demonstrated that adolescents and young adults regularly participate in behaviours that could increase their risk of anaphylaxis, such as eating unsafe foods. Their research also found that this age group does not reliably inform or teach their peers about their FA and how to treat it, nor regularly carry their adrenaline auto-injector with them during day to day activities.

Forming an identity is an essential aspect of adolescence as individuals work to fit in with their social group (Michaud, Suris & Viner, 2007). However, this can cause challenges for adolescents as they try to adapt to a more social lifestyle whilst managing a chronic condition. Whilst peer support and influences can be beneficial to help cope and lead to less risk-taking behaviour (Warren et al., 2017), peer support can also have a negative effect on illness management if adolescents do not want to appear different from those around them and adolescents with FA may choose to avoid discussions about their health because they worry that such discussions could make them appear different to their friends (Sampson et al., 2006). Adolescent studies have shown that peer influence is associated with risk-taking (Gardner & Steinberg, 2005; Knoll, Magis-Weinberg, Speekenbrink & Blakemore. 2015; Prinstein, Boergers & Spirito, 2001; Smith, Chein & Steinberg, 2014), and this has also been identified in adolescents with FA. For example, Sampson et al. (2006) attributed adolescents eating foods containing an allergen to peer pressure, as they took part in this behaviour more often when they were with their peers. A systematic review of adolescents and FA education found that they were more likely to take risks, including with their allergies, and increase the potential cause harm to themselves especially when with peers (Unruh, Gillespie, Ross & Becker, 2014).

Adherence to managing chronic conditions can be challenging during adolescence, and rates of adherence can vary. Calsbeek et al. (2006) argued that when prescribed diets are followed strictly, it is possible for adolescents with FA to live a 'normal' life. However, for individuals with FA, illness management involves a set of complex behaviours and lifestyle changes such as avoiding foods, avoiding certain situations and carrying medication (Jones et al., 2015), and these could affect how adolescents cope.

The systematic review in Chapter 3 identified the different types of coping strategies used by adolescents, however, only a small number of studies were included in the review and further primary data is needed to fully explore how adolescents use coping strategies to manage living with FA.

5.3. Aim

The principal aim of this study was to understand what coping strategies are used by adolescents with FA. The study also aimed to understand the experiences and contexts in which these coping strategies were used, and to compare these strategies with those used by children in similar settings (as described in Chapter 4). The CBMC was applied as the theoretical basis to contextualise the coping strategies identified.

5.4. Study design

This was a qualitative study, using semi-structured interviews. Ethical approval was granted by the South West and Frenchay Research Ethics Committee (15/SW/0316 – 36/10/2015).

5.5. Study setting

Semi-structured interviews were conducted with adolescents aged 12-16 years old either face-to-face at Aston University, in a private room at their home, or via a video-calling method using Skype. Locations were the choice of the adolescent and their parent. Parents were not present at the interview.

5.6. Recruitment

The study sample was recruited in the same way as children in Chapter 4, via an allergy clinic in Birmingham and through advertising by Allergy UK. Adolescents or parents of adolescents who expressed interest were sent or emailed an information package containing information sheets, one for the adolescent and one for the parent (Appendix 15 & 8). If they wished to take part in the study, adolescents were asked to contact the researcher to arrange a time and date to be interviewed.

5.7. Participants

Nineteen adolescents (n=12 girls, n=7 boys) participated in this study. The mean age was 14.2 years old (age range 12-16 years). Sixteen participants were recruited via Allergy UK and 3 participants were recruited from City Hospital, Birmingham. Seventeen participants were interviewed using Skype and two were interviewed face-to-face (one at their home, and one at Aston University).

All participants were prescribed an adrenaline auto-injector and antihistamines in either liquid or tablet form. Peanut was the most common allergen, followed by 'other nuts'. All but three participants had multiple FA. One participant had been diagnosed with her FA in the last six months prior to being interviewed at the age of sixteen, the remaining participants were diagnosed in infancy or early childhood (Table 5.1).

5.8. Procedure

The date, time and location of the interview was decided by the adolescent and his or her parents. Signed consent forms were either obtained at the home of the participant, or if conducting the interview via Skype, consent forms were emailed to the parent for them to complete with their child and sent back to me before arranging an interview date (Appendix 10 and 16). At the start of each interview I checked that the adolescent understood the nature of the study, that they knew their information would remain confidential and that they were free to withdraw at any time. A checklist was completed with the adolescent and parent about their FA (Appendix 11). All interviews were recorded and transcribed verbatim.

Table 5.1: Participant characteristics

Gender	Age	No. of allergies	Peanut	Other nuts	Cow's milk	Egg	Soya	Fish	Shellfish	Latex	Tree pollen	Grass pollen	Other
M	12	3			x	x							x
M	12	2		x			x						
F	12	7				x							x
M	12	2	x	x		x			x				x
F	13	3	x	x									x
F	13	2	x	x						x	x		
F	14	2	x	x									
F	14	3	x	x	x								
F	14	1	x										
M	14	2	x	x									
M	15	2	x	x									
M	15	5	x	x	x	x							x
F	15	1	x										
M	15	3	x	x									x
F	16	4			x	x			x				x
F	16	1											x
F	16	3	x	x					x				
F	16	4	x	x	x						x	x	x
F	16	5		x	x	x							x

5.8.1. Interview schedule

The same interview schedule that was used for children in the previous chapter was used to guide the interview (Appendix 12). For adolescents, additional questions were added to the schedule that were more relevant for adolescents, such as "how does having a FA affect your social life with friends?" and "how do you look after yourself when you go out with friends". These questions were added following a review of adolescent literature and the importance of peers and socialising during this period of life. Whilst the interview schedule acted as a guide, like Chapter 4, there was flexibility in the interview process to allow conversation and topics to develop naturally.

5.9. Analysis

The analysis of the data follows the methodology described in Chapter 4. The transcripts were analysed thematically using an abductive approach. Coding was primarily inductive, focussing on the experiences of the adolescents and their descriptions of behaviours used to cope with being allergic to food. This was followed by deductive thematic analysis by comparing the coping behaviours identified during inductive analysis with the three components of the CBMC to provide a contextual explanation to the findings. Like Chapter 4, coping strategies identified within quotes were categorised using the CBMC as either primary-control, secondary-control or disengagement coping (Appendix 17) before being combined with data from the rest of the participants (Appendix 18). Abductive reasoning took place through a recurring process of inductive and deductive analysis of the transcripts, with the process and findings discussed with the supervisory team as part of a reflexive process. My thoughts and experiences of the interview process were recorded in the reflexive diary, mentioned in Chapter 4, which helped me to understand how my own ideas about FA and experience of working with adolescent with chronic illnesses shaped my analysis.

5.10. Results

Four themes were developed from the data: "Unpredictable. That's what secondary school feels like"; "Now there's more to think about when I go out"; "It's not that bad to be me who's allergic to food, you know?" and "The changing role of social support". Coping strategies in this age group are associated with the experiences associated with the transition from childhood to adolescence, such as the changes in the social experience, their identity and levels of responsibility. In the written analysis, all participants are identified by their pseudonyms along with their age, e.g. William (14yrs). Coping strategies identified in the data were classified using the CBMC as either primary-control, secondary-control or disengagement coping.

5.10.1. Theme 1: "Unpredictable. That's what secondary school feels like."

For adolescents, secondary school was associated with greater potential for an allergic reaction, due to a new and different school structure, a greater number of students, and a new and widening social group. All of these presented challenges that could affect how adolescents coped with their FA.

Moving between classrooms was a particular concern, with adolescents such as Alex feeling that they were more at risk of an allergic reaction than before:

> *"It's all different, everything was done in the same classroom but now we're always moving around, and it feels really uhmm like you can't predict things, like I could have a reaction anywhere. Unpredictable. That's what secondary school feels like."*
> *– Alex (12yrs)*

Primary control coping strategies were used to help reduce the risk of an allergic reaction. Alex described using vigilance to be aware of his surroundings and ensure his safety. However, in his quote below, this method of coping was often integrated with worry or fear which could present itself as hypervigilance instead:

> *"I have to do like double, triple the amount of checking on the tables because we aren't in the same room all the time and I can't be sure if someone has eaten something before I've sat there. I'm always, always checking everywhere I go." – Alex (12yrs)*

Lunch times were generally unsupervised with increased autonomy over what food could be brought in and where lunch could be eaten, in contrast to the routine of primary school. This left Megan feeling uncertain about her safety as she perceived the risk of allergic reactions occurring to be higher. In addition, a greater variety of foods and number of students moving around with food was a cause for concern:

> *M: "But now we can go anywhere for lunch, dining room, common room, field, so it's totally different to how things were at primary school when we all ate in the dining room."*
> *I: Does that affect how you manage your food allergy? This new freedom I guess?"*
> *M: "Uhmm, I'd say that it's probably a bit more unpredictable because there's more people around, and there are more chances of things happening." – Megan (16yrs)*

Some adolescents were found to use disengagement strategies such as avoidance to cope with the unpredictability. Adam described occasionally eating his lunch in isolation away from his friends as a way of coping with the uncertainty of the food his friends were eating. In his quote, Adam seems to feel a loss of control over being able to know what his friends were eating which caused worry:

> *A: "At primary school, we all ate the same thing pretty much and that was fine. Mine was sometimes a bit different because of the nuts and stuff, but you knew what everyone was having. But now my mates could be bringing in anything, so I don't really know what they're eating."*
> *I: "Does that worry you then, not knowing what your friends are eating?"*
> *"[Laughs] Sometimes yeah. Sometimes I'll eat my lunch somewhere else because I worry, and I don't want to make a thing out of it." – Adam (15yrs)*

This was an experience also shared by Eleri, who described occasionally eating her lunch in the school toilets away from others to avoid an allergic reaction. Eleri felt she was unable to control the sheer number of students she may have come into contact with and removing herself from them was her way of coping, despite it resulting in isolation from others. At the time, isolation appeared to be preferred than risk of contact with nuts:

> *"In Year 7, I remember I'd eat my sandwiches really quickly in the bathroom because I was so worried that I'd come in contact with someone who had had nuts." – Eleri (14yrs)*

The majority of adolescents had 'nut ban' policies at their school. This could reduce the anxiety felt by some as nut bans were likened to a safety net. However, nut bans also appeared to diminish the importance and use of other coping strategies to reduce risk, such as vigilance, as Alice explained:

> *"I don't feel unsafe because we have a nut ban in school, so it's like a safety net. No one can bring in nuts, so I don't have to worry about eating away from my friends, or always watching where I'm sat." – Alice (15yrs)*

For others, nut bans did not reduce anxiety. A small number of adolescents described friends and peers breaking the rules and bringing nut-based foods. There were also concerns that peers may have been unaware that their food contained nuts and may have brought them in accidentally, and so the environment was never truly safe. As Rachel described, checking her surroundings was a sure way of being safe despite the nut ban:

> *"We have a nut ban, but people still bring in a snickers bar sometimes. And I think some of the kids don't realise that what they have has nuts in, so it doesn't make me feel that much safer, I wouldn't be able to relax about it, I'd still have to check." – Rachel (13yrs)*

A crucial part of the move to secondary school was the transition of responsibilities of medication and FA management. At secondary school, adolescents were required to carry their medication with them at all times, creating an extra burden:

> *"The teachers were in charge of my medication, they were the ones I would have to go to if I needed my tablets and stuff, but I have to carry it with me now all the time." – Rosie (14yrs)*

Remembering to carry their medication with them to school could be challenging. Despite recognising the importance of doing so, it could be easily forgotten, particularly in light of past experiences where carrying it was not required. Kirsty and Vijay often coped with their forgetfulness by relying on their parents to remind them to carry their medication, another form of primary-control coping:

> *"Uhmm, I after 7 years I still can't remember it and I still forget it and my Mum's always like have you got your EpiPen on you? And I always have to go and get it because I forget to pack it because she like always took care of it for me." –Kirsty (14yrs)*

> *"It's hard to remember still because my mums always in charge of it, even now, so I do rely on her to remind me to carry it." – Vijay (15yrs)*

Others learned to cope with this new challenge by using problem-solving strategies. For example, Simon described placing a note next to his school bag every evening which would act as a reminder in the morning to make sure he packed his medication with him. This helped Simon to develop a routine that reduced his reliance on this strategy:

> *"I use those sticky square notes and put it next to my bag that says, "check your medicine" to help me remember [laughs] but I don't need to do it all the time now." – Simon (12yrs)*

If medication was considered too problematic or inconvenient to carry to or around school, one adolescent would cope by purposely leaving his medication at home. As Adam explains, he occasionally left his AAI at home if he already had too much to take to school. He further justified his actions by stating that he would be careful with food and assumed that his school would have a spare AAI for him:

> *"Sometimes I have like science and English and sports on the same day, which is a lot of stuff for me to have in my bags, and then my sports bag too. So, I have sometimes, not like loads, only a few times, left my EpiPen at home because I can't fit it in my bag. But I'll be extra careful with food and things and I'm pretty sure the school would have a spare pen in the nurse's office anyway," – Adam (15yrs)*

Those who tried to make carrying medication easier, were found to use problem-solving strategies such as using smaller bags or pouches that would contain their medication when placed into their school bags. These served a dual purpose of keeping their medication organised and separate from other belongings, as well as easing the transfer between other bags that they might have. Organisation was key to ensuring that carrying medication was as easy as possible, as William explained:

> *"I have this pouch and make sure I have a specific section in my bag that's just for my medication, which makes it easier to carry." – William (14yrs)*

Adolescents also experienced a change in their social circle and interaction with peers at school. Fitting in at school is an important objective of adolescents (Crosnoe, 2011; Eccles & Roeser, 2011), and having a new social group could affect how adolescents coped with their FA. Whilst there was acknowledgement over the importance of disclosing their FA to friends and peers to stay safe, this could be challenging. Adolescents described a loss of familiarity established at primary school where they had been more comfortable talking about their FA. Alice did not attend secondary school with her primary school friends and described how her feelings of familiarity and comfort shifted to one of apprehension at having to 'start again' with disclosing her allergy to a new group of people:

> *"It was fine at primary school, everyone knew about my allergy but then when I went to secondary school, no one knew and I remember feeling really worried and nervous and stuff about having to tell people 'oh, I have an allergy', and having to start that conversation all over again because I haven't had to do it for the whole time I was at primary school." – Alice (15yrs)*

When it came to disclosure, gender differences were identified with some boys appearing to struggle more with disclosure than girls. This struggle was managed through use of disengagement coping

strategies. For example, Harry described how he would prefer to hide his FA from his friends at the start of secondary school as it was deemed easier than tackling the discussion with them early on. This was often due to fear of what his friends or peers would think:

> *"I didn't tell them about it for ages because it was just easier and less hassle. But eventually I did tell them, and it was fine." – Harry (15yrs)*

Rory would try to minimise the presence of his allergy by being discrete about reading labels and checking food and hiding his medication, rather than being open with his friends about his allergy:

> *"I remember just like, hiding reading the labels and, and checking what was in the packets and stuff, so none of my friends saw I was doing it because I hadn't told them I was allergic to nuts and stuff. I hid my EpiPen as well because they didn't know I was allergic, I didn't want them to know." – Rory (12yrs)*

In contrast, Rachel and Amelia were found to favour using primary control coping strategies by explaining their FA to their friend's right at the start of attending secondary school. Both girls felt that an open discussion early on to make their friends and peers aware of their FA was beneficial, in favour of using disengagement coping strategies such as hiding their allergy which could have serious consequences:

> *"So, when I first told them, I said like these are what I can't eat, this is what happens if I'm stupid and eat them, and here's how to use the pen [laughs] so that made things easier because it was over and done with telling them that like straight away and I didn't have to hide it." – Rachel (13yrs)*

> *"Telling them early on definitely helped because it meant they knew from the beginning that I can't have that stuff or that stuff could make me really ill." – Amelia (16yrs)*

Secondary school encompassed a range of challenges that adolescents had to cope with, and this appeared to be principally due to a change in routine, structure and familiarity. Coping strategies in this theme largely aligned to the primary-control and disengagement coping construct of the CBMC (Table 5.2). Primary control coping strategies were used to stay safe, particularly within a new environment that was linked to uncertainty and risk and could be used to help adapt to new routine, such as carrying medication. Disengagement coping strategies could also be used if the risk associated with this new environment was felt to be too high, or the pressure of adapting to routine too difficult. Such strategies could lead to social isolation, and risk of being unable to treat a reaction, which could have dangerous consequences.

5.10.2. Theme 2: "Now there's more to think about when I go out."

A significant change as part of adolescent life discussed by all of the interviewees was their increased autonomy and socialising without parents being present, a factor not identified in the younger children discussed in Chapter 4. Together, greater autonomy and independence presented additional

considerations for adolescents with FA, and they used a range of primary-control and disengagement strategies to cope with this.

A commonly mentioned activity amongst adolescents was eating out socially with friends without the supervision of parents. Although this new freedom could be exciting, it remained stressful for some. Adam explained how his social experiences were simpler in childhood and his FA didn't interfere with his social life as he didn't go into town to eat with friends when he was younger. As he grew older, he realised that being allergic to food meant extra considerations had to be taken, such as having to be mindful of where he could eat, and ensuring he had his medication with him:

"Things were definitely easier back then because I didn't do things like go out with my friends after school, or at the weekend and stuff like that, not like I do now and now there's more to think about when I go out with the allergies, like where can we eat, and taking my EpiPen with me." – Adam (15yrs)

Natalie also reported feeling the same way. Although she could go out and eat with her friends, they were not bound by the strict rules of adhering to a nut free diet as she was, which made her experience of eating far more complex. Unlike her friends, Natalie would always feel an element of worry when eating out:

"I can go out with my friends, but I still have to make sure I avoid anything with nuts. They don't have to have that worry, that they won't suddenly blow up like a balloon the second something with nuts touch their lips." – Natalie (13yrs)

Experiencing this type of stress could lead to social isolation and withdrawal as a way of coping. Whilst Adam didn't want his FA to affect his social life, he felt at times burdened by the extra 'stuff' he had to do in comparison to his friends. At times he felt that he 'couldn't be bothered' to go out if it required extra effort:

"I don't want it to affect my life and stuff and being able to go out with my friends, but they don't have this extra stuff that I have to do. Sometimes I just think I can't be bothered to go out because its extra effort." – Adam (15yrs)

A consequence of increased autonomy and a more active social life was having to learn how to cope with their FA in places that were previously seen as scary or high-risk (Chapter 4). Primary control coping strategies that were usually employed by parents were now the responsibility of adolescents, such as carrying medication out with them or enquiring about food content in restaurants, as Harry and Amelia explained:

"I do the checking now, I ask what's in the food, tell them about my allergies." – Harry (15yrs)

"Normally it would be my mum who would have my EpiPen in her bag, but when I go out with my friends, that's on me to carry it." – Amelia (16yrs)

Socialising without parents could also lead to coping with FA in unsafe ways, by using disengagement coping strategies such as minimisation by playing down the severity of their FA or avoiding disclosing

their FA to restaurant staff. These strategies could be used to cope with the emotional burden of disclosing the FA if it made them feel awkward or embarrassed, as Adam and Eleri explained:

"I just feel awkward about asking, so sometimes I don't ask and just order the food because it's probably going to be ok." – Adam (15yrs)

"Sometimes when I'm not eating with them (parents) I don't really tell the staff about my allergies and stuff because I don't know, I get embarrassed about it and stuff." – Eleri (14yrs)

Generally, adolescents such as Harry coped when eating out with friends by always choosing the same meal to avoid the risk of an allergic reaction. This was also identified in the previous chapter, and may have resulted from habits of eating out when younger:

"We normally go to Café Rouge or Prezzo and I always have the same thing when I'm there." – Harry (15yrs)

For some, it appeared that having parental supervision was the only way to feel truly safe in a high-risk environment such as a restaurant, as Kirsty explained. Her narrative is telling of the lack of control and self-confidence she feels in being able to safely manage her FA in public without her parents when wanting to try new foods:

"I only try new stuff when I'm with my Mum because she will be better at checking than I am." – Kirsty (14yrs)

Carrying medication when socialising outside of the home was an essential coping strategy to keep safe. As Kirsty explained, the risks of not carrying medication when out was too great as there was even less uncertainty of the types of foods that they could come into contact with. This was her way of being in control of risk and ensuring that she would be able to treat a reaction in an emergency:

"I always take my EpiPen with me when I'm out. It's because it's even more dangerous, I don't know what food I could come in contact with, it could just happen. But if I carry it with me, then I can do something about it if I have a reaction." – Kirsty (14yrs)

Boys could find it difficult to carry their medication with them in comparison to girls. All of the girls described taking small bags with them in town, however, none of the boys interviewed described using such a method, with one boy, Adam, believing that carrying bags was more associated with girls than boys:

"I don't carry a bag into town, I think that's more for girls, its fine for them to carry a bag but not really for boys so I don't have a bag to put my EpiPen in when I go out." – Adam (15yrs)

The majority of the boys interviewed carried their AAI with them in their pockets, despite the inconvenience of the size and shape of the device, as safety far outweighed the risk of being unable to treat an allergic reaction as Simon explained below:

"It really doesn't fit very well in my jeans pockets, but I have to carry it don't I? What if I had a reaction and didn't have it?" – Simon (12yrs)

However, one boy would leave his medication at home due to the inconvenience of carrying it in his pocket, rationalising that he would be fine without his AAI:

"It's just so bulky and hard to carry it around sometimes and annoying because it doesn't fit properly in my pockets, so I have just left it behind sometimes because I just think, 'Oh well, I'll be fine'." – Rory (12yrs)

Socialising independently with friends also presented opportunities to experiment with risk, particularly with foods that parents would not have allowed them to consume. For some, eating without their parents gave them freedom from strictly following the rules of safety, such as asking for an allergen menu or informing staff of their allergies:

"When I go out with my friends, it's not like going out with my parents where we have to always ask for the menu, tell them about my allergies, do this, do that. I can just go in, and order what I want to eat without going through that whole process. Like maybe I'll try something that might contain nuts in, it might not but if it's only may contain, it could only be a little thing, like my lips going tingly." – Alice (15yrs)

Unsafe foods could be even more tempting when parents were not around to intervene, as Sarah discussed. This meant that she would occasionally ignore the risks of eating dairy products, to which she was allergic to. Interestingly, Sarah appeared to modify the risk she was taking by trying to reduce the presence of food that was dangerous, indicating that she was mindful of the risks to her health. However, modifying the risk was also a way for her to justify the behaviour:

"We went out for some Italian food for my friend's birthday and they were all having pizza, and my parents weren't there, and I wanted to try some, so I had a small pizza. But I scraped most of the cheese off, so I'd be ok, and it was fine." – Sarah (16yrs)

A novel finding was the use of technology as a form of primary control coping to manage social outings. The accessibility of the internet whilst on the go could help adolescents to plan their meals ahead of their arrival, and check in advance whether a restaurant they were planning to go to could cater for their needs. By actively researching the food at their chosen restaurant in advance, Rosie and Jacqui were able to make more independent decisions about whether certain restaurants were suitable for them. Rosie demonstrated her increasing independence by her ability to suggest that her friends go elsewhere if the restaurant did not look 'ok':

"Uhmm, if I know where we are going to go eat, then I go on google on my phone and have a look at the menu and see what is there. If there's anything with cheese on then I can't have that [laughs]." – Jacqui (16yrs)

"Most of the time, places are fine for me to eat, but if we're all out and someone says let's get something to eat, then I always go online to their website and have a look at their menu and allergen menu's and if it really doesn't look ok for me to eat, then I'll suggest we go somewhere else." – Rosie (14yrs)

Not only did this help adolescents to plan in advance, it helped adolescents like Harry 'streamline' the process of choosing food at a restaurant, something he said in the past could take a while whilst he tried to navigate what he could and could not eat:

> *"Checking the menu on my phone really helps like streamline things and make the process smoother. Like, when I first started going out with my friends, it could take me ages to decide what to eat because I had to work out what was ok or not, now I just go on my iPhone and the menu is there." – Harry (15yrs)*

Socialising with friends and having increased freedom for adolescents presents challenges. Adolescents had to learn to how to cope in high-risk places without their parents. Some applied primary-control-coping strategies to stay safe, however, the use of disengagement coping strategies was also evident, particularly when socialising presented challenges that were difficult to manage. There could be a temptation to engage in experimental behaviours such as trying dangerous foods, however, interestingly, there was indication adolescents may be modifying the amount of risk they take by reducing, but not completely eliminating, the presence of allergens in food.

5.10.3. Theme 3: "It's not that bad to be me who's allergic to food, you know?"

Amongst the adolescents interviewed, identity was not only a poignant topic, but also a complex one. Like children in Chapter 4, coping strategies could be affected *by* FA identity, whilst strategies were also being used to cope *with* FA identity.

Harry expressed having concerns over what others thought of his allergy, whilst Megan felt that she had to "start again" when explaining her allergy to others as she became part of a new social group. At a time when adolescents felt pressure to fit in with their peers, integrating the FA into her identity and sense of self added to the emotional burden, causing worries as Megan describes below:

> *"I do get worried about what people think about me because of my allergies" – Harry (15yrs)*

> *"It was like having to start again telling people about my allergies and being the person that I am. And I didn't want to be that girl who was sick. It was yeah, it did used to make me worry a lot about what people would think" – Megan (16rs)*

Some worried that being known for having a FA would result in being treated differently by their friends as Eleri describes below, who was concerned that her friends would stop treating her like 'normal':

> *"Sometimes I worry about what do they think about the allergies, does it change what they think about me and things like that. Unless I'm having a reaction and itchy [laughs] you don't know I have an allergy, but I keep thinking that they probably think I'm always sick or something when I'm not and I don't want them to stop treating me like normal." – Eleri (14yrs)*

Adam was worried that having a FA would make him appear 'boring' and unable to partake in certain activities with his friends. In his quote below, he expresses a concern over social isolation resulting from his friend's perception of his FA:

"Sometimes I think, do they like, do they think I'm going to be boring and stuff because of my allergies and I can't do anything with them, 'cause I don't want them to leave me out of stuff." – Adam (15yrs)

Disengagement coping strategies, such as avoiding discussing FA, were identified as ways to minimise the presence of FA in order to appear as normal as their friends, as Adam explains below. His quote suggests that compared to his friends, he didn't perceive himself to be normal:

"I just try to avoid talking about it with them (friends) and act like I don't have it. I don't want to appear like I'm different, I just want to look normal." – Adam (15yrs)

Using disengagement coping strategies could help adolescents to appear "healthier" than they were to their friends. This was demonstrated by Eleri who spoke of occasionally downplaying the severity of her FA so as not to come across as someone who was "always ill". For Eleri, illness was associated with limitations, which she felt could potentially affect her social life:

"I just say 'Oh it's nothing really, no big deal, nothing to talk about', because it's easier than talking about it and I don't want them to think I'm always ill, so I don't get invited to stuff" – Eleri (14yrs)

Other adolescents interviewed refused to minimise their FA identity in order to stay safe, despite the repercussions this could have. Natalie, who was a victim of bullying because of her FA, explained that having a FA made her a target as she was perceived to be 'weak and ill':

"Yeah so, they make fun of me because I have a food allergy and I have to carry it (medication) around with me all of the time, so yeah like it's that on top of having allergies anyway. They only look at me for my allergies, rather than the actual me and the bullies probably see me as weak and ill because of it." – Natalie (13yrs)

Despite the bullying, this did not encourage Natalie to cope by hiding her FA or using other forms of disengagement coping. Natalie felt that her safety far outweighed the desire to minimise her FA identity in order to be appear more "normal" like her peers, even if this meant she could still experience bullying as a result:

"I don't uhmm hide it, people have to know anyway, they have to know I have a food allergy because if they don't then something really bad would happen. I'd rather they know than didn't, even if it means sometimes I'll be picked on for it." – Natalie (13yrs)

Despite the negative discourse that surrounded having a FA identity, only one adolescent spoke of hiding his FA from his friends and peers. The rest of the sample used secondary control coping strategies in place of disengagement coping and spoke positively about their condition and were accepting of their identity as an adolescent with FA. Those who coped with their FA in this way, such as Rachel and Jacqui, were able to be open about their FA rather than hide it and embraced who they were. As Jacqui said, her FA did not define her and her friends saw her FA as a part of her, and as something that was normal. This part of the quote contrasts with those above where adolescents didn't feel normal in comparison to their healthy friends and peers:

"I'm the only one in the group with an allergy, or generally an illness anyway, but like its fine. It doesn't stop me from taking care of myself, I still have to avoid foods, I still have my EpiPen on me. I tell them (friends), you know, I can't have that, and I'll have to read the labels and stuff before I can eat anything." – Rachel (13yrs)

"The allergy doesn't control me and doesn't define me, I take my EpiPen so I won't die, I read the menu and I avoid the foods and I am ok with that and my friends know that and they're ok with it too, like, they don't even care I have an allergy, they just see it as a part of me and it's normal." – Jacqui (16yrs)

Other secondary control coping strategies such as downwards social comparisons or positive reinterpretation, helped many to cope with having a FA identity. Adolescents were found to make comparisons with other types of FA, as well as with other types of chronic conditions as a way of coping. Adolescents who used these types of strategies focused on how much *easier* it was to manage FA or being allergic to a certain type of food and there appeared to be a FA or illness hierarchy. For example, Rachel found that making comparisons with others who had a dairy allergy made her feel better about her own peanut allergy. A peanut allergy was seen as something more people knew about in comparison to a dairy allergy:

"It's just peanuts, and I'd rather be someone who's allergic to nuts than something else like dairy, I think that one's a bit more unknown." – Rachel (13yrs)

Alice made comparisons between her FA with someone who was diabetic. She felt that her FA didn't make her stand out as much or placed such limitations on her in comparison to the medical needs she perceived of others with diabetes. In the quote below, she describes preferring being food allergic to being diabetic, which she saw as a more severe illness and one that would have a negative impact on how she was perceived as a person:

A: "It could be worse, like, I think it would be worse to be diabetic because you would always have to be injecting yourself and I think that would make it really difficult and make you really stand out. As long as I avoid the foods I'm meant to, I'll be ok really. I think, I think I prefer to have my allergy than have diabetes, I think that's worse, I think people would think I'm really sick or something, and I'm not that sick now."
I: "And did thinking about how it could be worse, or, as you said, being diabetic could be worse, help you cope with being this teenager that's allergic to food?"
A: "Yeah because it made me think, it helped because it's not that bad in comparison, like, it's not that bad to be me who's allergic to food you know?" – Alice (15yrs)

Some adolescents used positive reinterpretation in favour of disengagement coping strategies as a way of coping with and coming to terms with their FA identity. Adolescents were found to focus on what they could do, rather than what they were unable to do because of the FA. Both Rory and Amelia felt that they had more similarities than differences with their friends and having a FA identity was not necessarily associated with limitations. FA was viewed as only a small part of Rory and Amelia's identity:

"I don't see myself as different, I can still go out with them, I can still go to school, I can still go to Costas [sic] with them." – Rory (12yrs)

"Like, me and my friends, we all have the same life. Like me and my best friends, we get up and go to the yard to do my horse, and then go to college, have lunch at the college restaurant, go back down to the yard, do the rest of the lessons, then finish doing my horse, ride it, do whatever, and then come back up and have dinner, and then we both go to the bar together. Like we both do exactly the same thing and she doesn't have allergies." – Amelia (16yrs)

Many adolescents used phrases such as "I'm used to it now", "I've had it all my life" and "I've grown up with it", demonstrating a form of acceptance of their condition. The FA was a part of their 'normal':

"I've grown up with it now, like its normal for me." – Rachel (13yrs)

Similarly, Megan, who had been diagnosed very young, accepted that her FA was a part of her life. Being allergic to food was "normal" for her as she didn't know her life to be any different:

"I don't know any different, I've always not been able to have dairy so that's normal for me." – Megan (16rs)

However, this was different for Helen who was diagnosed with her allergy at sixteen years old, six months prior to being interviewed. Her narrative was distinctly different from the others, all of whom had been diagnosed in early childhood or infancy. Helen's narrative depicted a yearning for her pre-FA identity, mourning the loss of her healthy self and struggling to accept and adjust to her new diagnosis:

"I miss not having a food allergy, uhmm not being ill. I sometimes think back to when I was just normal and not like ill and I miss those days." – Helen (16yrs)

Helen had gone from being what she termed as a "normal teenager", one who she viewed as similar to her friends, who was healthy and could participate in social activities without worry, to a person with a FA diagnosis. In her eyes, FA became associated with ill-health and she became someone who was no longer normal or fit and healthy:

H: "I was a normal teenager and I was fit and healthy and now I'm not."
I: "In what way do you uhmm, not think you're normal?"
H: "Well I'm not like my friends, they don't have to worry about food and think about what they have to eat, where they're going. I've gone from being normal like them, to not." – Helen (16yrs)

Helen also had internal preconceptions of what types of FA she termed as normal, again demonstrating a FA hierarchy. She considered her FA to rapeseed oil as abnormal in comparison to other types of FA.

"It's not like the, uhmm, other food allergies. The more, you know, normal ones like nuts." – Helen (16yrs)

With this new diagnosis, Helen described having difficulty in coping with her FA safely. Whilst she described doing her best to avoid as many foods as possible, she often wondered if there was any point in avoidance as it was a difficult task. With her type of allergy, labelling was not always clear, and she described how rapeseed oil could be labelled as vegetable oil in many food products, adding to the difficulty in safely avoiding the allergen. Consequently, she wasn't always successful at preventing

reactions. Rather than take risks with her health, Helen was found to adopt other disengagement coping strategies instead as way of ensuring her safety, such as distancing herself from social activities with her friends that involved food as she was still lacking confidence in keeping herself safe:

"I just don't really go out with them if they're going somewhere to eat, I don't feel safe yet." – Helen (16yrs)

Identity can have an important role in the types of strategies used to cope with a FA. For adolescents who did not want to appear or be perceived as different, disengagement coping strategies were favoured as a way of supressing their FA identity to appear more 'healthy' or 'normal'. Disengagement coping strategies, such as avoidance, was also used by one adolescent with a recent diagnosis of FA. However, for those who did not have a negative perception of having a FA, primary control coping strategies by informing others of their FA were identified. Secondary control coping strategies were found to help adolescents cope with having a FA identity, in particular, the use of positive reinterpretation and downward social comparisons.

5.10.4. Theme 4: The changing role of social support

Despite increased autonomy, social support was still identified as an important coping strategy for adolescents, however, its uses appeared to change with the onset of adolescence. Relying on parents to carry and manage medication and risk management was something many adolescents no longer did, and they described this as a normal part of 'growing up' as they assumed more responsibility in other areas of their life:

"It's just part of growing up, I guess. My Mum does less with my food allergy now and I do more for it, but I do more stuff now for myself anyway like when I'm at school or out with my friends, I'm more independent now." – Alice (15yrs)

Many adolescents were thinking ahead to their future, where parental supervision would be further reduced, particularly when living away from home. Amelia spoke of her future at university and was mindful that her life would be changing from one that was dependent on her parents for all aspects of her life, including FA management, to one that would see her become more independent as she moved throughout her life:

"I would say that I don't really ask my parents for help with my allergy anymore, not now I'm like 16 and at college and stuff. It's like, well, I'm older now and I have to take responsibility for it because I'll be on my own a lot more soon." – Amelia (16yrs)

An interesting narrative was identified amongst older adolescents in the group (aged 15 and 16) where uses of instrumental social support, particularly through parents, were being described in the past tense, alluding to the former roles their parents once had. Both Harry and Megan's narrative suggested a decline in the use of instrumental social support and an increase in the use of other primary control coping strategies, indicative of the transition from dependence to independence:

"I've been doing things on my own now without asking Mum and Dad for help, like getting them to do stuff for me like carry my EpiPen and stuff which they used to do." – Harry (15yrs)

"I've definitely been a lot more carrying my medication and things, because I used to just give it to my mum to carry when I was smaller, but now I don't need her to help with me that." – Megan (16yrs)

In place of using instrumental support, other primary control coping strategies were adopted. In Harry and Megan's quotes above, both describe using other types of primary control coping strategies, such as carrying their own medication with them. These were among strategies also identified in the previous themes where parental supervision was reduced, for example, at school or socialising outside of the home. However, carrying medication remained a contentious issue, particularly for boys. A small number still relied on their parents to carry their medication for them when going out. Relying on their parents was a way for these boys to cope when they were unable to carry it themselves as Alex illustrated:

"My Mum and I have sometimes gotten into arguments about this, like who carries the EpiPen. She says I should because I'm a teenager now and I'm not a child anymore. But she, like I don't have a bag that I carry round with me, and it doesn't fit in my pockets or my jacket very well, so I have to ask her to carry it for me." – Alex (12yrs)

The use of instrumental coping could also result from a lack of confidence these adolescents had. For example, both Eleri and Harriet expressed a lack of confidence in their abilities at checking food content at restaurants and explaining their FA to staff. Both girls felt that their parents were 'better' than them at these tasks, leading them to seek instrumental support to cope when eating out at restaurants:

"If we're eating out, I normally get my Mum to tell them I have a food allergy and what I can't have, uhmm she's better at it than me so I have her do it." – Harriet (12yrs)

E: "I ask my parents to check for me whether my food is ok or not."
I: "Would you sometimes ask the staff if the food is ok yourself or?"
E: "Uhmm, I just prefer it if they do it because they're better at it than me and know what they're saying." – Eleri (14yrs)

Whilst seeking instrumental support can be perceived as a form of primary-control coping, it could also, to an extent, be viewed as a form of disengagement coping. William explained that being with his parents afforded him the opportunity to relax about risk management and allow someone else to take the reign. Independently coping with his FA in places such as restaurants could be a burden for him which he wanted to avoid:

"When I go out with them, it like gives me a chance to relax about it because it can be quite a pain to always tell people about my allergies and check the food, and it's just nice to let my parents do it for, give me a bit of a break [laughs]." – William (14yrs)

Some adolescents sought support from friends. This mostly occurred within a social setting where adults or parents were not present. These friends appeared to become substitutes for parents. For example,

Sarah explained how she would sometimes ask her friends to check if a restaurant had an allergen menu and was safe for her to eat at if they were arranging a meal, a role her parents would often have if they were arranging a family meal out:

"If they're like planning a meal or something, I'll ask them to check if they have an allergen menu or dairy free food so I can eat there as well, it's funny because like my Mum or Dad would do that too [laughs]." – Sarah (16yrs)

Friends could also help with risk management. Megan described enlisting the help of her friends to search for appropriate food at a supermarket during a school trip. Asking her friends for help on this occasion, helped speed up the process of finding something to eat in a supermarket chain she was unfamiliar with:

"We were on a school trip once and we all went to Sainsburys to get food and snacks and we don't shop at Sainsburys as a family, our nearest supermarket is Tesco, so I'm not really familiar with their free from range. So, I asked my friends to help me because it would be much quicker, I told them what to look for, like the word milk will be in bold." – Megan (16yrs)

Emotional social support as a coping strategy was more widely discussed and wasn't subject to the past tense narrative of instrumental social support. Talking to others in a bid to offload negative feelings associated with their FA or to seek comfort, was used as a way of coping when the FA left adolescents feeling worried or low in mood. Parents were also primarily approached for emotional support by adolescents, alongside older siblings with FA if this was an option. Parents could alleviate the worries and stress of their adolescent children by providing comfort or reassurance. As Natalie explains, her parents could understand the root cause of her feelings having cared for her with her FA:

"It helps talking, usually I'll talk to Mum about it because she knows how stressful it is because I've had it all my life and how upset I can get about it." – Natalie (13yrs)

Older siblings with FA could provide a unique source of emotional support, as they have a lived experience of FA. Eleri, who's older sister also had a FA, felt that the similarities in lifestyle and mutual empathy about the condition afforded her with a type of emotional support that her parents could not provide as they did not have a FA. Her sister could provide reassurance and advice when she was feeling worried about the transition from secondary school to college or university, having been through that experience herself:

E: "My sister is at college and stuff so I've asked her 'Oh how is it at college with your nut allergy, were people mean about it and stuff?'"
I: "Are you worried about what it could be like at college or as you get older with your allergy?"
E: "A bit, but Katy said that it's fine and we've talked about it a lot like how she did it and how it's not like, not really different from school so I feel ok about it, so it doesn't really worry me much now" – Eleri (14yrs)

Similarly, Amelia felt that the emotional support her older brother with a FA provided was 'different' to her parents, as he could fully empathise with why she would be feeling frustrated or low:

A:"If I'm like having a bad day or anything, you know, like fed up with the food allergy and stuff then I call him up sometimes and chat with him and it helps make me feel better."
I: "Do you get the same sort of advice from your parents?
A: "I get advice from them obviously but from him (brother) it's different from theirs."
– Amelia (16yrs)

Unlike instrumental social support, seeking emotional social support from friends was not reported. Seeking emotional social support from family members was preferable over friends as it was felt that friends (in particular, those without a FA), would be unable to empathise with the difficulties associated with being allergic to food:

"I wouldn't really go to them (friends) because I don't want to make a thing of it and it's just easier to talk to my parents about it." – Adam (15yrs)

One barrier to seeking emotional support was described by Megan who didn't want to burden her friends if she was feeling worried or sad. Megan was more concerned over the negative impact it would have on her friends if she spoke to them about her FA worries or concerns. In her quote below, Megan describes her concerns around placing a burden on her friends:

"I don't want to be on their case when I'm feeling worried about it and stuff, I don't want to burden them with my problems." – Megan (16yrs)

The use of professional support was not widely reported. This was discussed by just one adolescent Natalie, who had access to a school counsellor, and also sought additional support from a clinical psychologist through her allergy clinic, as a way of dealing with the emotional burden resulting from her FA, such as anxiety:

"I was just getting really down about it (food allergy) and stuff so I've seen her (clinical psychologist) a few times through the hospital. I've seen a school counsellor too."
– Natalie, (13yrs)

Natalie also provided an insight into the process of accessing professional support which was not straightforward:

"We were supposed to do it (see a clinical psychologist) through the hospital but because of where we live and what hospital we go to, none of the psychologists accepted to have me so we're having to move hospitals because of that." – Natalie (13yrs)

Peer support groups were also not widely reported. But for one adolescent, Helen, peer support would have been helpful for her as she tried to come to terms with and live with her FA. Having what she felt was an uncommon FA to rapeseed oil, meant she felt limited in terms of the support she could access as she was unable to find support groups that catered for her FA. Of the one group she had managed to find

online, accessibility was then further challenging as the support group appeared to be inactive, and therefore, she was unable to get any peer support at all.

"I requested to be a part of a rapeseed allergy group, but it's taking a while for my request to get accepted so I can't access anything" – Helen (16yrs)

This left Helen feeling alone, unable to voice her feelings or concerns with others with the same FA, or get advice. She was instead having to search the Internet to try and find an answer to her questions or to seek information about her FA. As she described in her quote below, websites were a poor substitute for advice from someone living with a rapeseed allergy.

"There isn't much on rapeseed oil at the moment, so it's frustrating, and I can't find any groups except for that one that isn't really busy. so, all I can do is, uhmm, go on the Internet and search for things if I need to find an answer to something, but websites aren't going to tell me things and give me advice in the way another person with my allergy could." – Helen (16yrs).

Despite adolescence being associated with increased autonomy, social support remains an important coping strategy for adolescents. Instrumental and emotional support is sought from a variety of people, and parents remain an important source of this support. However, the extent of seeking instrumental support from parents appeared to lessen, possibly due to increased autonomy. Friends appeared to have a role for providing support for adolescents, however, this was confined to assisting with the practical elements of FA management, rather than for emotional support.

5.11. Discussion

This qualitative study provides a unique, in-depth account of how adolescents cope with FA. The themes identified in this study appear to be influenced by the experiences associated with the transition to adolescence whilst living with a chronic condition: "Unpredictable. That's what secondary school feels like"; 'Now there's more to think about when I go out"; "It's not that bad to be me who's allergic to food, you know?" and 'The changing role of social support'. The present study supports and further adds to the FA literature, by specifically exploring coping strategies in young people with FA which is underpinned by applying a CBMC to the data to draw out the various coping strategies.

5.11.1. Main findings

Adolescents were found to use a range of primary control, secondary control and disengagement coping strategies, which could vary dependent on situation or environment (Table 5.2). The strategies identified were not strikingly different from children in the previous chapter, however, the experiences did differ with the transition to adolescence.

Table 5.2: CBMC constructs attributed to each theme

Theme	Primary-control coping	Secondary-control coping	Disengagement coping
Theme 1	• Carrying medication • Informing friends and peers of FA • Problem solving • Vigilance of surroundings	• Not identified in this theme	• Physical avoidance (school canteens)
Theme 2	• Carrying medication • Enquiring about food content • Choosing safe meals • Using internet – problem solving/planning	• Modifying risk to manage emotional arousal "it'll be fine"	• Withdrawal from /avoiding socialising • Minimising FA • Not disclosing FA to staff • Leaving medication at home
Theme 3	• Informing others	• Positive thinking • Downward social comparisons • FA / illness hierarchy • Acceptance	• Physical avoidance • Withdrawal • Minimising FA
Theme 4	• Independently carrying medication • Seeking instrumental support • Seeking emotional support	• Not identified	• Avoidance discussing FA with others

Secondary school was widely discussed by every adolescent, which supports the "transitional adjustments" coined by Fenton et al. (2011) to describe the experiences of adolescents entering high school. Secondary school encompassed a number of structural differences that caused stress, similar to previous findings, such as, moving classrooms, 'unregulated' lunches (i.e. those provided by parents and not by the school) and a widening social circle (Fenton et al., 2011) and was the largest theme to emerge from the data. Primary-control coping strategies such as vigilance could help to manage the increased risk of cross contamination and exposure to unsafe food, however, indications of hypervigilance were also identified in one boy, which corroborated the findings of a study where such strategies were observed in adolescents in uncertain situations (Fenton et al., 2011).

Unregulated lunches at secondary school could be stressful as there was greater agency in the type of food others could bring and where they could eat, supporting the findings of a Canadian study where adolescents felt high school posed greater potential risk due to structural differences such as common eating spaces and unsupervised lunch areas (Fenton et al., 2011). Disengagement coping strategies such as avoidance were identified when adolescents chose to eat lunch separately from friends rather than asking friends to be more careful, which has also been reported previously (Stjerna, 2015). As controllability of the stressor is central to the coping strategy used (Compas et al., 2012), it is possible that adolescents who used disengagement coping strategies found unregulated lunches difficult to

control, particularly having transitioned from primary school where lunches were consistent and controlled.

A previous study identified that boys struggled to carry medication with them to school due to inconvenience (Macadam et al., 2012). Whilst inconvenience relating to size and shape of the AAI device was mentioned in this study, only one boy reported on occasion leaving his medication at home if he had too much to carry to school. What this study also found, were the uses of primary control coping strategies, such as problem-solving, to make the process of carrying their medication easier and reduce the inconvenience.

Discussing or disclosing FA to new friends or peers at secondary school was challenging, especially for boys who discussed using disengagement coping strategies to minimise or hide the presence of their FA. Similar findings have been identified in previous literature in adolescent boys who have experienced teasing or bullying (DunnGalvin et al., 2009). Teasing or bullying was only mentioned by one girl in this study, but it is possible that the concerns around teasing or bullying may have played a part in the use of minimisation to cope in this study, particularly as identity, discussed later on in the study, was a pivotal issue for adolescents.

The second theme identified in the data concerned managing FA when socialising and becoming more independent. Reduced parental oversight helped adolescents to develop their autonomy as well as apply coping strategies that their parents may have used. In line with previous research (DunnGalvin et al., 2009;Mackenzie et al., 2010; Marklund et al., 2007; Monks et al., 2010) adolescents tended to be careful when eating outside of the home and used primary-control coping strategies such as making enquiries about food content, asking for specialist menus, or disclosing their FA to staff. However, eating without parents could be stressful and some adolescents were found to choose the same meal to avoid a reaction, comparable to findings of previous research (DunnGalvin et al., 2006; Calsbeek et al., 2006). Whilst this could arguably be a form of primary control coping as they were minimising the risk of an allergic reaction, this prevented some adolescents from feeling comfortable in trying new foods, even if they enquired if the food was safe or not.

The issue of burden was expressed by some adolescents, who felt the increased responsibility for having to think about their FA when making their own choices about what was safe to eat. This has been found in previous literature where burden was experienced by adolescents who expressed frustration at having to check their food is safe to eat (Mackenzie et al., 2009). An interesting finding were the forms in which burden could take, with practical burden such as carrying medication, checking food content, and emotional burden, such as dealing with feelings of embarrassment, awkwardness and anxiety. Both types of burden could be managed by disengagement coping strategies such as minimisation of the FA, by suppressing its existence, leaving medication at home if inconvenient to carry it, or withdrawing from socialising with friends. These behaviours have been described before, for example, Gallagher et al.

(2011) identified that some adolescents would not carry their AAI with them if it was cumbersome to carry, suggestive of it being a practical burden. Furthermore, DunnGalvin et al. (2009) identified that some children and adolescents would not mention their FA to others to manage emotions such as anxiety, suggestive of an emotional burden of FA. The use of disengagement coping strategies may suggest that some burden can be difficult to control, and it may be easier for some adolescents to avoid the stress of such burdens by using disengagement coping strategies.

Socialising independently also presented opportunities for adolescents to engage in risk-taking behaviour, such as not alerting members or staff of their FA, or consuming unsafe foods, behaviours that have been previously described (Akeson et al., 2007; DunnGalvin et al., 2009; Mackenzie et al., 2010; Marklund et al., 2007; Monks et al 2010; Sampson et al., 2006; Fenton et al., 2011). Reduced parental oversight had a role in the temptation to engage with risk, a finding that is shared across adolescents with a range of chronic illnesses, such as diabetes (Ellis et al., 2007; Wasserman, Anderson & Schwartz. 2017). However, in contrast to other research (Sampson et al., 2006; Greenhawt et al., 2009; Monks et al., 2010; Warren et al., 2017), this study did not find that many adolescents regularly participated in risk-taking behaviours, with only a small number describing such behaviour. Many adolescents in the current study prepared for unplanned social events and researched where they would be eating in advance. This fits with the findings of Gallagher et al. (2012) that the 'stereotypes of teenagers as reckless appear inaccurate and over-generalised' (p. 396).

A novel finding of the current study was the use of technology to plan for eating out, using smart phones to search the internet to check food menus and decide if a restaurant offered choices of food that were suitable to eat. This has not been previously identified in the FA literature but supports recent findings of a study that researching adolescents' perspectives on using technology for health (Radovic, McCarty, Katzman & Richardson, 2018) where authors identified one of the main uses of technology was to gather information to support their health.

Additionally, this study identified that risk behaviours could be modified by the adolescent, e.g. eating dangerous foods but removing a large portion of the ingredient that is unsafe. Rolison & Scherman (2002) have suggested that adolescents take part in risk if they believe that consequences can be controlled. It is possible that adolescents with FA who describe engaging in risk behaviours may be modifying the risk to a level they feel they can control. Modifying risk to reduce danger, reveals that adolescents can also be mindful of their safety. This demonstrates the use of primary control coping as adolescents take steps to minimise the stressor, albeit for a different purpose.

Identity is a pivotal topic in adolescence, as adolescents both with and without chronic illness experience the challenges of identity and the desire to fit in with their peers. The present study identified that coping strategies could be affected *by* identity, and strategies were also used to cope *with* identity. For adolescents in this study, their identity was closely tied to their condition. Disengagement coping

strategies to minimise the presence and severity of FA were used by adolescents who were concerned about how others would perceive them. Such strategies were used to hide what made them different from their friends and is similar to findings of previous research both in FA and other chronic illnesses such as epilepsy (DunnGalvin et al., 2009; Eklund & Sivberg, 2003). Additionally, in the present study, minimisation strategies were used and had the purpose of making adolescents appear healthier than they were, as identified in the example given by one adolescent boy who minimised his FA so as to appear 'normal'.

In this study, more boys were identified using disengagement coping strategies that minimised the presence of FA compared to girls, thus rejecting their FA identity. But a FA identity did not always lead to disengagement coping strategies if the benefits of making the FA known outweighed the resulting impact such as bullying. This contrasts previous research where experiences of bullying could lead to rejection of a FA identity (DunnGalvin et al., 2009). The greater use of disengagement in this way by boys in this study may be explained by the finding by Williams (2000), that boys can find signs of illness as potentially stigmatising, whilst girls can accept their illness within their social and personal identities.

Secondary-control strategies appeared to have the most use when it came to coping with the FA identity. Strategies such as downward social comparisons, positive reinterpretation and acceptance are behaviours that have been identified before in similar circumstances (Fenton et al., 2011; Mackenzie et al., 2009; Marklund et al., 2007). Adolescents in the present study made comparisons to other FA, similar to findings by Mackenzie et al. (2009) and Marklund et al. (2007). However, unique to this study, they also made comparisons to other chronic illnesses as being much worse to manage than FA.

The use and efficacy of secondary control coping strategies to manage their identity was found to be impacted by duration of diagnosis in the adolescents in this study. Previous research has identified that those who had been diagnosed longer, were more accepting of FA as a way of life (Mackenzie et al., 2009). This supports the findings of the present study, as struggles accepting FA identity was identified in the adolescent with a recent diagnosis of FA. However, in contrast to Mackenzie et al. (2009), this resulted in the use of disengagement coping strategies, rather than primary control coping strategies. It is likely that a shorter duration of time since diagnosis can affect confidence in self-management, but how one responds could depend on other factors associated with duration of diagnosis, such as knowledge of how to manage their FA which may be limited compared to someone who has been diagnosed with FA since childhood.

Social support was the final theme identified in the data and was used as an important coping strategy. But, seeking instrumental support from parents appeared to decline as adolescents got older, corroborating the findings of a review into the development of coping by Skinner and Zimmer-Gembeck (2007). These findings are also in line with previous research on adolescents with FA, for example, Gallagher et al. (2012) found that adolescents took on more responsibility for their FA management,

such as medication or checking food ingredients. Being reflective of the future also appeared to play a role towards the move to independence. Whilst this is likely to be associated with events such as preparing for A-levels and university, it is possible that as FA comes with responsibilities, adolescents are forced to think about the future and what is expected of them, more than their peers without a chronic illness. Some adolescents however, lacked confidence in their ability to manage their FA and they continued to rely on parental support, particularly when eating outside of the home. This could suggest that for some, transition to autonomous management does not always happen straight away when a child reaches adolescence. It is possible that there may still be a need for reliance on parents to help cope particularly when confidence is an issue.

A number of adolescents in this study sought instrumental support from friends, and this appeared to coincide with the decline in using parental support. This also again aligns with the findings of the review by Skinner and Zimmer-Gembeck (2007) who concluded that this shift occurs due to the decline in seeking support from adults. As also reported by Stjerna (2015), adolescents in the current study appeared to ally themselves with friends that supported and understood their allergy. However, this did not appear to be the case for emotional support which was predominantly sought from parents, or siblings with FA. Similar to previous research (DunnGalvin et al. 2009; Macadam et al. 2012; Mackenzie et al. 2009; Monks et al. 2010) adolescents expressed concerns around a lack of understanding of FA which is likely to have prevented them from seeking that type of support from friends when needed.

Finally, difficulties in accessing psychological therapies may have been a contributing factor towards the limited reported use of professional support, both in this and the previous chapter. FA can lead to impaired quality of life, and high levels of stress and anxiety (Teufel et al., 2007). Having the support of health professionals could facilitate the development of more adaptive coping strategies to manage the challenges of FA. It is also possible that this was not reported in the interviews, or adolescents may have not felt comfortable discussing it, rather than as a reflection on the effectiveness of professional support as a way of coping with FA related difficulties.

5.12. Strengths and limitations

This study is the first to specifically explore coping strategies in adolescents aged 12-16 years with FA that applies a CBMC. Strengths lie in the qualitative nature of this research, which has allowed an in-depth exploration of the experiences of adolescents with FA. Analysis of the data by applying a CBMC has allowed to me to extend upon and understand the types of coping strategies that are used by adolescents and when.

Adolescents were recruited across the UK, and not confined to one geographical area, which allowed for variation in their characteristics and their experiences, such as schooling and access to allergy clinics, to be included in the data.

However, there are limitations to this study. Like that of Chapter 4, the majority of interviews were conducted over Skype, and the limitations regarding this are similar to that of Chapter 4. Whilst the use of video-calling was useful to read facial expressions, it is possible that elements of body language that may have alluded to an answer different to that which the adolescent was telling me was missed. No parents were present during the interview with adolescents. However, for adolescents who were interviewed at home, whether this was over Skype or face to face, there may have been an awareness that parents would be nearby, and possibly able to hear the interview, which may have influenced the answers given by adolescents.

Only one adolescent was interviewed at the University. Though a neutral setting, again, the lack of familiarity of home surroundings may have impacted the interview and how the adolescent answered my questions. Being interviewed at home, may have elicited different responses, or may have given that adolescent the opportunity to show what they used or what helped them cope with their FA.

Limitations also lie with regards the sample of adolescents in this study, like that of Chapter 4. Firstly, there is an imbalance of gender in this study, with almost twice as many girls than boys taking part in the study. Given that gender can influence coping (Williams, 2000), it is possible that this study is missing the in-depth detail and experiences of adolescent boys. Limitations also lie in how representative this sample is of adolescents with FA more broadly. Like that of Chapter 4, the data is drawn from a majority White-British sample, with only one British-Asian participant, thus missing the perspectives of adolescents with FA from different cultures and ethnicities. The majority of adolescents interviewed were allergic to peanuts and nuts, which may have biased the data obtained and conclusions drawn. Additionally, like that of Chapter 4, adolescents who took part in this study were generally coping well and may have been encouraged by their parents to participate in this study because of this. This means that this study is lacking in qualitative data from adolescents who are not coping well and are struggling with their FA, or who are poorly supported by their parents and could be coping differently.

Further research could look to investigate the different sub-sets of FA and identify if there are any differences between the coping strategies used, and why this may be. Only two participants had a diagnosis of a single FA, with one of these participants having a recent diagnosis of FA in later adolescence. Therefore, the perspectives and coping strategies identified from the analysis of the results of this data are from a sample where the majority are diagnosed with multiple FA, and who have been diagnosed for longer (i.e. since childhood). These factors will also affect the development of the coping scale as the data is biased towards adolescents with these profiles. Future research that involves participants with recent diagnoses of FA could add further meaning and understanding to the coping strategies used, and if there are differences in coping strategies compared to those with a longer diagnosis of FA.

Despite these limitations, this study provides a valuable insight to the experiences of adolescents with FA and the coping strategies they use in different situations.

5.13. Conclusion

This study has identified that adolescents use primary control, secondary control and disengagement coping strategies to cope with FA. Coping strategies are influenced by a number of factors, such as environment, transition to independence and increased autonomy, and a widening social circle and peers. Subsequently, as demonstrated in the thematic map (Figure 5.1), primary control coping strategies are more focused on independent, active coping strategies such as problem-solving (including use of technology to facilitate this), vigilance and carrying AAIs rather than those that utilise social support which whilst remain present, play a supporting role in the roster of strategies adolescents use. Factors that can make adolescence complex, such as identity, also play a role in the coping strategies used and this appeared influential in the types of disengagement coping strategies identified in this population. From the thematic map, disengagement coping strategies included many strategies that sought to suppress the FA identity through minimisation, hiding and not disclosing FA to others. Secondary control coping strategies were also used to cope with FA and identity issues, and is in keeping with how children in Chapter 4 also used secondary control coping strategies. There was evidence of adolescents avoiding social situations where food was the focal point, such as school lunchtimes. Again, one must consider the influential role of parents in how adolescents perceive their own risk in social situations. As discussed in Chapter 4, avoidant strategies may be heavily influenced by their parents own anxieties surrounding their child's illness, which may influence adolescents to remain fearful of and avoid social situations as they grow older (DunnGalvin & Hourihane, 2009; Fox et al. 2005; Skinner & Zimmer-Gembeck, 2007).

Future research could look to understand gender differences, as well as differences between other types of FA and its effects on coping strategies used as there appeared to be a subtle difference between how adolescents boys and girls coped, in particular with use of disengagement coping strategies. Additionally, more research should be conducted to understand the effect of a later diagnosis in older adolescence, and the impact this has on adjusting to life with a chronic illness. Finally, developing a scale to identify coping strategies may help to identify how adolescents are currently coping, and who may be struggling. Appropriate interventions could be developed that help adolescents use more adaptive coping strategies, and reduce risk, particularly as this age group is associated with FA fatalities (Pumphrey & Gowland, 2007).

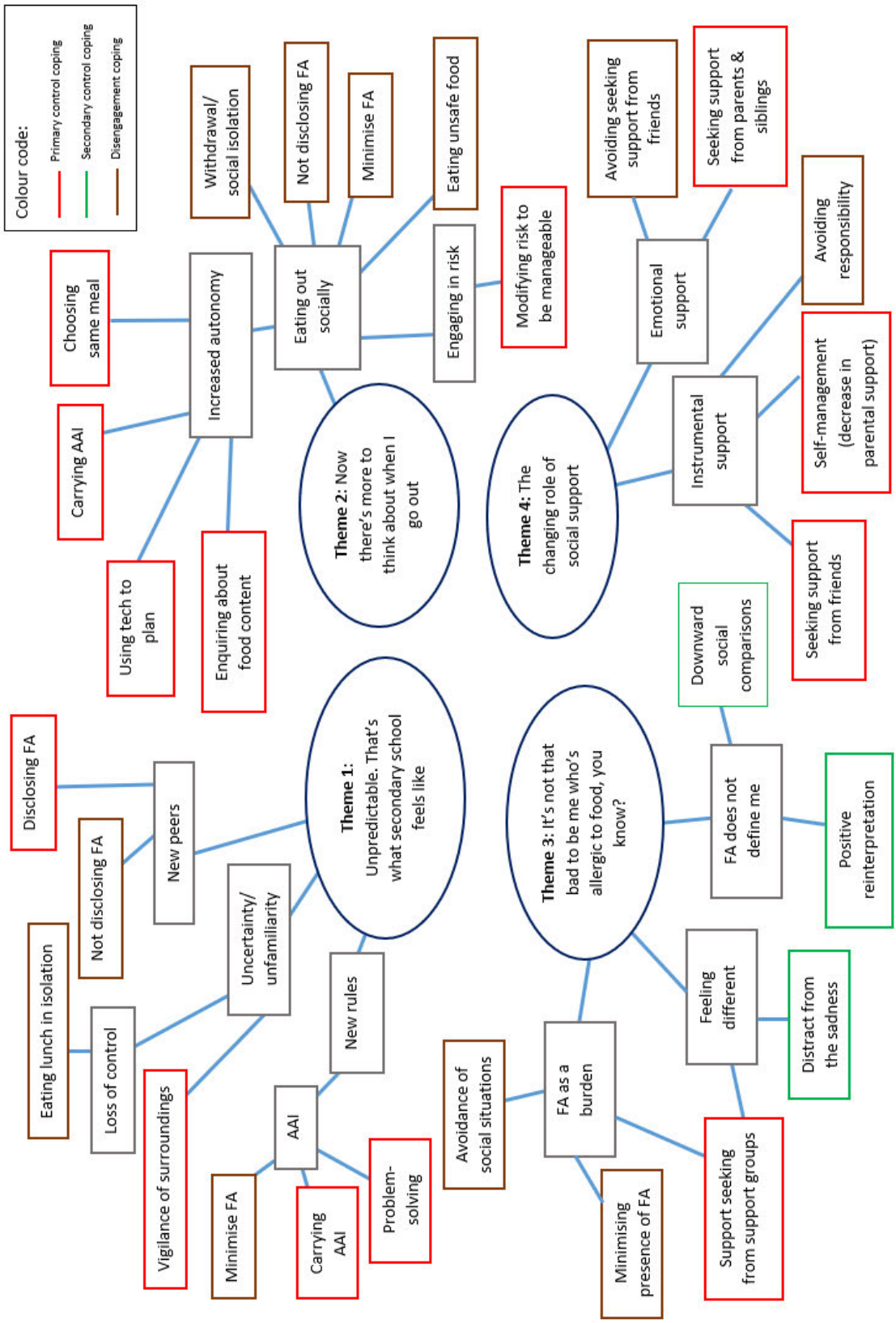

Figure 5.1: Thematic map of adolescent's coping strategies using the CBMC

CHAPTER 6 The development and validation of the Coping Scale for Food Allergy (CS-FA)

6.1. Introduction

In this chapter, I introduce and describe the development and validation of the Coping Scale for Food Allergy (CS-FA).

As described in Chapter 1, generic PROM's are not designed to capture areas of concern of specific patient populations. For example, they may include items that are irrelevant to the patient group or miss issues specific to the feature of the disease or condition that is being studied (McKenna, 2011). Measures that are developed using a needs-based approach are disease-specific and allows a focus on the specific needs and makes them highly relevant and acceptable to the patient concerned (McKenna, 2011).

Outcome measures have a necessary role both in research and clinical practice as they can objectively measure the outcome being studied, provide an insight into the patients view of their own health as it is directly reported by the patient themselves, and provide a means of tracking symptoms or function over time (Johnson, 2008). Measures based on the CBMC have been developed, such as the Response to Stress Questionnaire (RSQ), and adapted for a number of chronic conditions, such as diabetes, cancer and chronic pain (Compas et al. 2006; Compas, Desjardins, Vannatta, Young-Saleme, Rodriguez, Dunn, et al., 2017; Jaser, Patel, Xu, Tamborlane & Grey, 2017) though no generic RSQ exists. Whilst it could be argued that one of these disease specific RSQs could be adapted for FA, this could potentially lead to items that are not relevant to children and adolescents with FA as the initial development of these items would be based on a different patient population. Furthermore, the age range that the RSQ can be administered to is above that of the age range of the participants in my thesis, with children having to be at least 9 years old to complete the RSQ. Therefore, adapting an RSQ for FA for the age group of my study would be inappropriate.

To address this issue, a coping scale specific to FA was developed to capture and identify the coping strategies of children and adolescents with FA. When this study was conceptualised and designed, there were no coping scales specific to FA for children and adolescents aged 8 to 16 years old. DunnGalvin et al. (2018) have since developed a preliminary FA coping and emotions scale for children, adolescents and young people aged 6-23 years old, by conducting deductive TA on secondary data obtained from interviews with participants across a number of studies conducted in Australia, Ireland, Italy, UK and USA. However, an issue with conducting secondary data analysis is that the original data would not have been collected to answer the present research question (Tripathy, 2013), and analysis is conducted on the primary author's interpretations of their participants accounts, what is known as a triple hermeneutic (Smith, Flowers and Larkin, 2009).

As mentioned in Chapter 1, it is important to measure coping as how individuals cope can have an effect on how well they are adapting to their illness, their QoL and psychological functioning. However, it is also important that such a scale should be developed using primary qualitative data to minimise the issues associated with analysing secondary data. Therefore, a coping scale was developed using primary, qualitative data obtained from semi-structured interviews children and adolescents aged 8-16 years old with FA from Chapters 4 and 5.

6.2. Method

The development of the CS-FA followed the guidelines set out by the FDA (2006) for the development of patient reported outcome measures for use in clinical trials, and guidelines to scale development by Pesudovs et al. (2007), DeVellis (2017) and Carpenter (2018). This study was granted ethical approval by the South West and Frenchay Research Ethics Committee (15/SW/0316 – 14/07/2017).

6.2.1. Item generation

Items for the CS-FA were developed from the in-depth interviews with children and adolescents aged 8-16 years old with FA discussed in Chapters 4 and 5 (see Chapters 4 and 5 for demographic and FA details of the participants).

The formulation of statements was achieved in a two-part process. The first part consisted of identifying quotes from individual interviews and grouping them according to a particular topic, for example, medication (see Appendix 19 for examples). Quotes were then reviewed within their categories and separated out according to types of coping behaviour or strategy, for example, two strands were identified in the topic 'medication' which were 'carrying medication' and 'not carrying medication' (see Appendix 20 for example). Following this process, the grouping of quotes was then reviewed with the supervisory team as part of a reflexive process and to ensure quotes were being represented correctly according to the coping strategy they were matched with. Statements were then formulated using the coping behaviours or strategies identified within the categories, using the quotes as a guide, for example "I carry my medication with me in case I have an allergic reaction". During this process it was clear that coping strategies extracted from the interview data were relevant to all ages of participants apart from coping with socialising without adult supervision, which were identified in the 12 to 16 age group only. I therefore decided to create one scale for ages 8-16 years, with some additional items for adolescents aged 12-16 years old who went out socialising without adult supervision.

Version 1 of the prototype CS-FA (see Appendix 21) consisted of thirty-five core questions, and six additional questions relating to coping with FA when socialising without adult supervision for adolescents aged 12-16 to answer. Questions were worded as statements and participants rated to what extent they used that strategy on a 5-point Likert scale: 1 – Never, 2 – Not very often, 3 – Sometimes, 4 – Most of the time, 5 – Always. The questions were not designed to be reverse scored. The prototype scale underwent cognitive testing (Chapter 2) with three children (aged 8, 10 and 11) and three

adolescents (aged 13, 14 and 16). Cognitive interviews were conducted individually, and each child and adolescent were asked to go through each question, describe how they would answer it, why they would answer it that way, and how clearly the statements and the Likert scale were worded and if it was easy to understand. If any statement appeared to be difficult to answer, participants were asked to explain what made the statement difficult to understand, and what would help make it easier to understand or if they had suggestions for alternative phrasing. They were also asked if the scale represented the aspects of coping with a FA, and whether anything important was omitted and should be included.

The majority of children and adolescents felt that the wording of point 2 of the Likert scale 'not very often' was confusing and thought it to be too similar to the wording of point 3 'sometimes'. The word 'rarely' was suggested by many participants as a replacement for 'not very often' as it was viewed to be different enough from 'sometimes' and 'never'. One child and one adolescent felt that the term 'medication' was too broad as they were only prescribed an AAI. Therefore, separate questions were created for AAI's and antihistamines to reflect this. In addition, those who did not answer 'always' to carrying either type of medication, were asked to write their reasoning in the free text box below to understand whether it was because their parents carried their medication for them or because the child chose not to carry it with them. As the scale was developed for both children and adolescents to complete, based on the feedback from children, the wording of statements was simplified. For example, "If I am having an allergic reaction, I prefer having someone else to administer my medication" was reworded to "If I need to use my adrenaline auto-injector (e.g. EpiPen, JEXT), I prefer someone else to do it for me". The additional questions for adolescents aged 12-16 were also commented on by children below this age group. The children aged 10 and 11 felt that they would be able to answer those questions, an interesting observation as qualitative data in chapter 4 did not reveal children socialising on their own without parents unless visiting a friend's home. Following this feedback, it was decided that these questions would be optional for any participant of any age to answer (See appendix 22 for a summary of comments and suggestions made to each item).

In addition to the cognitive interviews, the prototype scale was sent to a panel of experts comprising two consultant allergists, a nursing representative from the charity Allergy UK, two health psychologists specialising in FA and scale development, and one paediatric clinical psychologist with experience of working with children with chronic health conditions. Feedback regarding wording and additional questions were received from the panel. Upon reviewing the feedback, and in conjunction with feedback obtained from the cognitive interviews, additional changes were made to the prototype scale leading to the final prototype scale comprising 43 core items, and 6 optional items for those socialising with a parent present, as well as an optional free text box at the end of the questionnaire for children and adolescents to write down anything else they would do to cope with their FA (see Appendix 23 for the final prototype scale).

6.2.2. Testing the prototype CS-FA

Participants eligible for this part of the study had to be aged 8-16 years old with a clinical diagnosis of FA. The study was advertised through allergy clinics across Sandwell and West Birmingham Hospitals NHS Trust, and nationally using social media such as Facebook and Twitter, and advertisement in newsletters by Allergy UK. There is mixed opinion over the optimum number of participants needed to conduct PCA. Tabachnik and Fidel (2007) suggest a sample size of 300 is 'comforting for factor analysis' (pg.613), whilst other schools of thought recommend that one should follow a participant to item ratio which can vary from five participants to ten participants per item (Pallant, 2011). This study followed the recommendations of Tabachnik and Fidel (2007) and aimed for 300 participants to complete the pilot CS-FA.

The prototype CS-FA was distributed in two ways; paper format and online. The paper version of the CS-FA was distributed via allergy clinics in Birmingham or posted to the participant if requested. It is unknown how many packs were distributed by the allergy clinics in Birmingham as these numbers were not recorded by the clinics. In addition to the CS-FA was an information pack comprising an information sheet for parents and age appropriate information sheets for participants (Appendices 24, 25, 26) consent forms for both parent and participants (Appendices 27, 28, 29), a demographic and allergy checklist also used in chapters 4 and 5 (Appendix 11) and four validation scales; KidCOPE, Revised Children's Anxiety and Depression Scale (RCADS), Food Allergy Independent Measure (FAIM) and the Brief Illness Perception Questionnaire (B-IPQ). As the KidCOPE and FAIM have scales for different age groups, packs were separated for 8-12-year olds and 13-16-year olds. A fifth validation scale, the Food Allergy Quality of Life Questionnaire (FAQLQ) was not administered at this point due to concerns around participant burden. However, it was expected that a large proportion of children and adolescents who completed the prototype CS-FA, would opt in to participate in the test re-test phase of this study and I would be able to achieve a high number of participants completing the FAQLQ at a later point.

The online CS-FA was completed using the survey software package Qualtrics. Like the hardcopies of the questionnaire, the information sheets were uploaded onto Qualtrics for prospective participants and their parents to download and read before continuing with the study. Consent was taken on Qualtrics with both parent and participant asked to sign with their signature using their mouse or their finger if using a mobile phone or tablet (Appendices 30, 31 and 32). Without a signature and completion of the consent form, participants could not proceed with the study. Following consent, the CS-FA, demographic and allergy checklist (Appendix 33) and the four validation scales could be completed on Qualtrics. The questionnaires were set up on Qualtrics so that participants could not continue to the next questionnaire unless all questions had been answered, to avoid the likelihood of missing data. However, there was still a possibility for participants to miss out questions on the hardcopy of the questionnaire. For this, missing variables would be treated pairwise, which is a common approach to dealing with missing data (Kang, 2013). Two separate surveys links were created for ages 8-12 and 13-16 depending

on the age requirements of the validation scales, and both links were advertised by Allergy UK on their social media platforms and through their e-newsletters. For both hardcopy and online version of the CS-FA, participants were asked if they would be happy to be contacted again with regards to the study.

6.2.3. Test re-test of the reduced CS-FA

Once factor analysis, reliability and validity analysis had been conducted on the prototype scale, a test re-test was conducted. Children and adolescents who took part in completing the pilot CS-FA and who opted into be contacted again regarding the study, were invited to complete a re-test of the CS-FA on Qualtrics to assess for consistency of the CS-FA over a two-week period. Invites were sent out to ninety-five children and adolescents. At Time 1, children and adolescents were asked to complete a consent form for both participants and parent, the CS-FA alongside the FAQLQ. The FAQLQ was included in this round of testing to assess validity of the new scale. As previously mentioned, the FAQLQ was not administered during the validation phase of the CS-FA due to concerns around participant burden. However, it was expected that a large proportion of children and adolescents who completed the prototype CS-FA, would opt in to participate in the test re-test phase of this study, and a similar number would complete the FAQLQ. Two weeks after completing Time 1, children and adolescents were sent a link to complete the CS-FA again. Prior to completing the CS-FA again, they were asked to answer three questions; whether they had an allergic reaction, had to see a doctor because of their FA and whether they had to go to hospital because of their FA in the last two weeks.

6.2.4. Cross-sectional validation measures

The following measures were used to assess for cross-sectional validation:

The KidCOPE

Developed by Spirito, Stark and Williams (1988), the Kidcope is a self-report measure assessing coping behaviours, with versions for children aged 7-12 years old and adolescents aged 13-18 years old (Appendix 34 & 35). The Kidcope is divided into two parts; one to rate a problem situation that they either generate themselves or are given, and in the second part, to rate a series of coping strategies. Children must rate if they use a strategy on a two-point Likert scale ‘yes’ or ‘no’, and indicate its efficacy on a three-point Likert scale “0 – not at all, 1 – A little, 2 – a lot”. Adolescents rate if they use a strategy in the same way as children, however, efficacy is measured differently. This is measured on a five-point Likert scale “0- Not at all, 1 – A little, 2 – Somewhat, 3 – Pretty much, 4 – Very much’. Adolescents also rate the frequency that they use a given strategy on a four-point Likert scale, “0 – Not at all, 1-Sometimes, 2, A lot of the time, 3 – Almost all the time”. Calculating the efficacy of each coping strategy provides a measure of how helpful these strategies are. If a child or adolescent indicates that they do not use a given strategy, their efficacy scores for that category are ignored. The KidCOPE consists of the following subscales:

Distraction: (example item for ages 7-12: “I try to forget it”, example item for ages 13-18: “I thought about doing something else; tried to forget it and/or went and did something like watch the telly or play games to get it out of my mind”) .

Social withdrawal: (example item for ages 7-12: “Stay on your own”, example item for ages 13-18: “I stayed away from people; kept my feelings to myself, and handled that time on my own”).

Cognitive restructuring: (example item for ages 7-12: “Try to see the good side of things”, example item for ages 13-18: “I tried to see the good side of things and/or concentrated on something good that could come out of it”).

Self-criticism: (example item for ages 7-12: “Blame yourself for causing the problem”, example item for ages 13-18: “I realised I brought the problem on myself and blamed myself for causing it”).

Blaming others: (example item for ages 7-12: “Blame someone else for causing the problem”, example item for ages 13-18: “I realised that someone else caused the problem and blamed them for making me go through this”).

Problem-solving: (example item for ages 7-12: “Try to sort out of the problem”, example item for ages 13-18: “I thought of ways to solve the problem; talked to others to get more facts and information about the problem and/or tried to solve the problem”).

Emotional regulation: (example item for ages 7-12: “Try to calm yourself down”, example item for ages 13-18: “I tried to calm down by talking to myself, going for a walk and/or I just relaxed”).

Wishful thinking: (example item for ages 7-12: “Wish the problem never happened”, example item for ages 13-18: “I kept thinking and wishing that this had never happened and/or that I could change what had happened”).

Social support (example item for ages 7-12: “Try to feel better by spending time with others like family, grown-ups or friends”, example item for ages 13-18: “I turned to my family, other adults or friends to help me feel better”).

Resignation: (example item for ages 7-12: “Do nothing because the problem can’t be solved”, example item for ages 13-18: “just accepted the problem, because I knew I couldn’t do anything about it”).

The checklist has moderate to high validity when items were correlated with the Coping Strategies Inventory, with coefficients ranging from .33 to .77 (Spirito et al., 1988). The authors do not report the Cronbach’s alpha for this scale; however, Cronbach’s α for the total scale in this study was .66 for ages 8-12 and .88 for ages 13-16. The KidCOPE was selected as Pesudovs et al. (2007) recommends testing for criterion validity of a new instrument with one that measures a related construct. As this scale measures child and adolescent coping and was suitable for the age range of the participant population of my thesis, it was deemed to be an appropriate measure for this purpose.

Revised Children's Anxiety and Depression scale (RCADS)

Developed by Chorpita, Moffitt and Gray (2005), the RCADS is a 47-item scale that measures the reported frequency of various symptoms of anxiety and low mood for children aged 8-18 years old (Appendix 36). The items are rated on a 4-point Likert-scale from "0 -never" to "3 - always". A total anxiety and low mood score is produced, with separate scores for the six sub-scales which are:

Social phobia – 9 items: (example item: "I worry when I think I have done poorly at something")

Panic disorder – 9 items: (example item: "When I have a problem, I feel shaky")

Major depression – 10 items: (example item: "I feel worthless")

Separation anxiety – 7 items : (example item: "I worry about being away from my parents")

Generalised anxiety – 6 items: (example item: "I worry about things")

Obsessive-compulsive – 6 items: (example item: "I have to do the same things over and over again – like washing my hands, cleaning or putting things in certain order")

It also yields a Total Anxiety Scale score (sum of the 5 anxiety subscales) and a Total Internalising Scale (sum of all 6 subscales). Higher scores indicate a clinical threshold to anxiety and depression. The questionnaire has good validity when correlated with the Child Depression Inventory and the Revised Children's Manifest Anxiety Scale, with coefficients ranging from .59 to .72. Chorpita et al. (2005) reported the following Cronbach's α for the RCADS scales; separation anxiety .78, social phobia .87, obsessive compulsive .82, panic disorder .88, generalised anxiety disorder .84 and major depressive disorder .87. In the present study, Cronbach's α for the total scale in this study was .95, separation anxiety .79, social phobia .86, obsessive compulsive .74, panic disorder .85, generalised anxiety disorder .79 and major depressive disorder .88.

The RCADS was selected as symptoms of anxiety and depression can be associated with the types of coping strategies used (Compas et al., 2012). For example, uses of primary-control coping and secondary-control coping have been associated with reduced symptoms of anxiety and depression in children and adolescents with chronic pain, diabetes and cancer. Conversely, using disengagement coping strategies has been associated with more symptoms of anxiety and depression in children and adolescents with these health conditions.

Food Allergy Quality of Life Scale (FAQLQ)

Developed by Flokstra de Blok et al. (2008), the FAQLQ is a self-report measure of FA specific quality of life. There are versions for children – FAQLQ-CF (aged 8-12 years old) and adolescents – FAQLQ-TF (13-17 years old) (Appendix 37 & 38). The FAQLQ-CF has 24 items that are rated on a 7-point Likert scale ranging from "Not troubled" to "Extremely troubled". The FAQLQ-TF has 23 items that are rated on a 7-point Likert scale, ranging from "0 – Not troubled" to "6 – Extremely troubled".

The FAQLQ-CF comprises four domains:

Allergy avoidance (AA): (example item: "How troublesome do you find it, because of your food allergy, that you have to read food labels")

Risk of accidental exposure (RAE): (example item: "How troublesome do you find it, because of your food allergy, that you must watch out when touching certain foods")

Emotional Impact (EI): (example item: "How frightened are you because of your food allergy, of an allergic reaction")

Dietary restriction (DR): (example item: "How troublesome do you find it, because of your food allergy, that you must always watch what you eat")

The FAQLQ-TF comprises three domains;

Allergy avoidance and Dietary restriction (AADR): (example item: "How troublesome do you find it, because of your food allergy, that you are able to eat fewer products")

Risk of accidental exposure (RAE): (example item: "How troublesome do you find it, because of your food allergy, that the label states: "May contain (traces of)….?")

Emotional Impact (EI): (example item: "How frightened are you because of your food allergy, of an allergic reaction")

The FAQLQ-CF and FAQLQ-TF has good validity when correlated with the FAIM, with coefficients of 0.56 and 0.76 respectively. For the FAQLQ-CF Flokstra-de Bok et al. (2008) reported a Cronbach's α of .94. In this study, the Cronbach's α for the total scale of the FAQLQ-CF was .96, and for the following subscales: AA .91, RAE .76, EI .89, and DR .89. For the FAQLQ-TF, Flokstra-de Bok et al. (2008) reported a Cronbach's α of .92. In this study, the Cronbach's α for the total scale was .97, and for the following subscales: AADR .92, RAE .93 and EI .92.

The FAQLQ was selected due to the associations found between quality of life and coping in chronic illness literature. For example, maladaptive coping strategies can negatively impact QoL, whilst adaptive coping strategies, such as cognitive restructuring, can positively impact QoL (Compas et al., 2012; Gonzalez-Echevarria, Rosario, Acevedo & Flores, 2018; Jaser & White, 2011).

Food Allergy Independent Measure (FAIM)

Developed by Flokstra-de Blok et al. (2008) and later validated by van der Velde et al. (2010), the FAIM is an independent FA measure with 4 items related to expectation of outcomes (EO) that measure the severity of perceived risk of an accidental allergic reaction and the risk of not being able to treat a reaction appropriately, and two independent measure (IM) questions that reflect aspects of the perceived severity of FA that are not captured by the EO questions.

Example EO item for children: "How big do you think the chance is that you will accidentally eat something to which you are allergic". Example IM item for children: "How many foods are you unable to eat because of your food allergy".

Example EO item for teenagers: "How great do you think the chance is that you will accidentally eat something to which you are allergic". Example IM item for children: "How many products must you avoid because of your food allergy".

The FAIM is based upon an independent measure originally developed for patients with yellow jacket allergy (Oude Elberink et al., 2002). The FAIM child form is for children aged 8-12 years old (Appendix 37), and the FAIM teenager form is for ages 13-17 years old (Appendix 38). EO questions are rated on 7-point Likert scale ranging from "0- never (no chance)" to "6 – always (100% chance)", with a higher score indicating a higher level of perceived seriousness. The FAIM has shown good test-retest reliability with intraclass correlation and concordance correlation coefficients above 0.70. Cronbach's α for the FAIM is not reported by the authors; however, in the present study the Cronbach's α for the child form was .61, and .51for the teenage form.

The FAIM was selected as it examines specific constructs of FA that no other measure possesses, and has been previously used as a construct validity measure for the FAQLQ-CF/TF-AF for this reason.

Brief Illness Perception Questionnaire (B-IPQ)

Developed by Broadbent, Petrie, Main and Weinman (2006), the B-IPQ is a nine-item scale designed to rapidly assess cognitive and emotional representations of illness (Appendix 39). Participants' rate items on an 11-point Likert scale that form dimensions of illness perceptions. These are:

Consequences: example item: "How much does your illness affect your life")

Timeline: (example item: "How long do you think your illness will continue?")

Personal control: (example item: "How much control do you feel you have over your illness?")

Treatment control: (example item: "How much do you think your treatment can help your illness?")

Identity: (example item: "How much do you experience symptoms from your illness?")

Coherence: (example item: "How well do you understand your illness?")

Emotional representation: (example item: "How your illness affects you emotionally?")

Illness concern: (example item: "How concerned are you about your illness")

The authors do not report the Cronbach's alpha for this scale; concurrent validity has been measured with the Revised Illness Perception Questionnaire (IPQ-R), with equivalent scales of the B-IPQ and IPQ-R showing appropriate correlations ranging from .32 to .63. Cronbach's α for the total scale in this study was .66.

The BIPQ was selected as illness perceptions (based upon the common-sense model, Leventhal et al., 1984) can shape coping behaviour, for example, personal and treatment control has been found to be related to using active coping strategies and cognitive reappraisal (Hagger & Orbell, 2003). The BIPQ has been administered to children over the age of 8 with a wide range of illness and has indicated good psychometric properties (Broadbent, Wilkes, Koschwanez, Weinman, Norton et al., 2015). This shorter measure was also preferred over the revised illness perception questionnaire (IPQ-R) due to concerns of burden to participants over the number of measures they would be asked to complete.

6.2.5. Data analysis

Data was analysed using IBM Statistical Packages for Social Sciences (SPSS) Version 23 and FACTOR, a programme developed to fit Exploratory Factor Analysis models (Lorenzo-Seva & Ferrando, 2006).

A parallel analysis was first run on FACTOR to assess dimensionality (Timmerman & Lorenzo-Seva, 2011), and identify the number of components to be used during Principal Components Analysis (PCA).

PCA was then conducted using SPSS with varimax rotation to reduce the number of items of the CS-FA and to assess for structural validity. Varimax is an orthogonal rotation, used if one expects factors to be independent. It is one of the most commonly used methods of rotation, and the goal of varimax rotation is to maximise the variance of factor loadings, making high loadings higher and low loadings lower (Tabachnick & Fidell, 2007).

Cronbach's α was used to assess internal consistency of the scale. Construct validity was assessed using Pearson's correlations and t-tests, comparing scores of each component of the CS-FA with the scores of the four validation measures; KIDCOPE, RCADS, FAIM and BIPQ. Discriminant validity was also assessed by comparing scores between gender, ethnicity, allergy type, number of allergies and hospital admission due to an allergic reaction. Finally, intra-class correlations were conducted to look at the temporal stability of the scale over a two-week period. ICCs are widely used as a reliability index for test re-test purposes (Koo & Li, 2016).

6.3. Results – Testing the pilot CS-FA

6.3.1. Descriptive statistics of participants

One hundred and fifty-one children and adolescents took part in the study and completed the CS-FA, 55% males (n=83), 45% females (n= 68). Of these, only 113 also completed all four validation measures, 55.8% males (n=63) and 44.2% females (n=50). Therefore, factor analysis and reliability analysis were conducted with 151 respondents and validity analysis was conducted with 113 respondents. There were challenges with recruitment, and uptake of participants completing the scales was slower than anticipated. Whilst allergy clinics across Birmingham were given hardcopy questionnaires to give to prospective participants, it is unknown how many were given out. To aid with recruitment, the charity

Allergy UK, advertised the study on their social media pages online and via their newsletters which were emailed to members of the public who were signed up to receive them.

There was no missing data for the 113 respondents who completed the CS-FA and the validation scales. Table 6.1 describes the descriptive statistics of participants who completed the CS-FA only and those who also completed the validation scales. As demonstrated in the Table 6.1, a large proportion (>80%) of the 151 respondents who completed the CS-FA only were White-British, with smaller percentages associated with the rest of the ethnic groups captured. Furthermore, of the 151 respondents, there is a large percentage of respondents with peanut allergy (>70%), followed closely by 'other nuts' (>50%), and nearly half of these respondents indicated that they had 3 or more FA. These trends remain similar for the 113 (of the 151) who completed the CS-FA plus validation scales. It is important to bear this in mind, as these factors are likely to affect the final development of the CS-FA, and that the final CS-FA may be more suited to respondents who fall into these criteria better than those who do not.

To my knowledge, detailed data on the demographics of families with children with FA in the UK is not available. However, we are able to examine the participant demographics of child and adolescent FA studies based in the UK , which have indicated similar trends regarding the proportion of different types of FA. In a study by Jones et al. (2015), 'White' participants accounted for 81.5% of the participant population, followed by 'Black' (7%)','Mixed-race'(6%) and 'Asian' (3.7%). Whilst my participant population were fewer in percentage, the proportion represented by the different ethnicities reflects the participant population of the study by Jones et al. (2015). Additional studies based in the UK by Akeson et al (2007); Gallagher et al. (2011); Gallagher et al (2012); Mackenzie et al. (2009) and Sommer et al (2014), demonstrated a large proportion of their participant population having a diagnosis of peanut allergy followed by other types of nuts or tree nuts, again similar to the participants in this study.

Table 6.1: Demographics of participants for CS-FA and test re-test

Variable	Summary statistics			
	CS-FA only (n = 151)		**CS-FA plus validation scales (n = 131)**	
Age	Mean	11.55	Mean	11.94
	SD	2.825	SD	2.862
	Min.	8	Min.	8
	Max.	16	Max.	16
Gender	N	%	N	%
Male	83	55	63	55.8
Female	68	45	50	44.2
Ethnicity	N	%	N	%
White-British	122	80.8	88	77.9
White – Irish	4	2.6	3	2.7
White – other	5	3.3	4	3.5
Black or Black British – Caribbean	4	2.6	4	3.5
Black or Black British – African	1	0.7	1	0.9
Asian or Asian British – Indian	2	1.3	2	1.8
Asian or Asian British – Bangladeshi	1	0.7	0	0
Asian or Asian British – any other Asian background	1	0.7	1	0.9
Chinese	2	1.3	1	0.9
Mixed – White and Black Caribbean	1	0.7	1	0.9
Mixed – White and Black African	2	1.3	2	1.8
Mixed – Any other mixed background	5	3.3	5	4.4
Any other ethnic origin group	1	0.7	1	0.9
Allergy type	N	%	N	%
Peanut	110	72.8	85	75.2
Other nuts	87	56.6	61	54
Egg	55	36.4	39	34.5
Milk	58	38.4	40	35.4
Soya	12	7.9	9	8
Fish	15	9.9	13	11.5
Shellfish	27	17.9	22	19.5
Number of allergies	N	%	N	%
1 allergy	40	26.5	33	29.2
2 allergies	39	25.8	29	25.7
3+ allergies	72	47.7	51	45.1

6.3.2. Item reduction

Item reduction was conducted on the core 43 items of the CS-FA. As the online version of the scale was set up so that all items had to be answered, there was no missing data. Multicollinearity between variables scoring r> .80 were first assessed by screening the correlation matrix (Field, 2009). Three pairs of items were identified that correlated above >.80. These pairs were: item 18 (If I feel upset about my food allergy, I prefer to be by myself.) and item 19 (If I feel angry about my food allergy, I prefer to be by myself.), item 33 (If I'm feeling upset about my food allergy, I distract myself by doing things that I

like.) and item 34 (If I'm feeling angry about my food allergy, I distract myself by doing things that I like.) and item 29 (If I feel upset about my food allergy, I talk to someone close to me about it.) and item 30 (If I feel angry about my food allergy, I talk to someone close to me about it.). One item from each pair was removed – items 19, 34 and 30. The decision to remove these items were based on reviewing the data from the qualitative empirical studies (Chapters 4 and 5), which were more focused on children and adolescents expressing that they felt upset rather than angry about their FA, when talking about the emotional implications of FA. Floor and ceiling effects were also checked for, and these show the proportion of participants who have rated the item with the highest or lowest score. A floor and ceiling effect can be considered present when there is more than 15% of participants achieving these minimum or maximum values (Cöster, Karlsson, Nilsson & Carlsson, 2012; Lim et al., 2015), and whilst this cut off point was considered, the distribution of each item was also examined. Eleven items demonstrated floor effects, and twelve items demonstrated ceiling effects (see Appendix 40). No further items were removed at this stage as these questions were considered of importance for FA, such as such as the question "I carry my adrenaline auto-injector (e.g. EpiPen, Jext) with me in case I have an allergic reaction", where the majority of participants answered that they always carried their medication. Additionally, these items were coping strategies identified in my systematic review in Chapter 3, and qualitative data in Chapters 4 and 5. Finally, the sample size was not large enough, and nor solely recruited from allergy clinics to justify removing items based on floor and ceiling effects.

A further method of reducing items is to use the clinical impact (CI) methodology (Juniper, Guyatt, Streiner & King, 1997). CI is calculated as the product of the frequency and importance rating of each item by the respondents of the scale. However, CI was not used as a method of reducing items of the CS-FA as looking at the demographics of the participants in this study who completed the CS-FA, the sample was skewed towards White British participants with multiple FA. I felt that items selected on this basis may not be representative of what is considered to be important for the UK population of children and adolescents with FA overall.

6.3.3. Principal components analysis

As discussed in Chapter 2, there are a number of methods that can assist with determining the number of factors to retain. Prior to running a PCA, a parallel analysis of the remaining 40 items was run on FACTOR (Timmerman & Lorenzo-Seva, 2011) to assess for dimensionality (Timmerman & Lorenzo-Seva, 2011). The output indicated 6 factors (Table 6.2). Factor 1 accounted for 16% of the variance, with factors 2, 3 and 4 accounting for 10%, 8% and 6% of total variance respectively (Table 6.3). There was minimal change in total variance identified between factors 4 and 5 (1.9%) and factors 5 and 6 (0.4%). As over-dimensionalisation can occur with large numbers of items, where a larger number of factors has been retained than is justified (van der Eijk & Rose, 2015), it is possible that this matrix indicating 6 components had been overrepresented.

Table 6.2: Parallel analysis output

Variable	Real-data eigenvalues	Mean of random eigenvalues	95th percentile of random eigenvalues
1	6.45260	2.14710	2.27810
2	4.22889	2.00528	2.10567
3	3.31259	1.89617	1.97777
4	2.74550	1.80567	1.87668
5	1.96879	1.72530	1.79857
6	1.46333	1.65205	1.71910

Table 6.3: Explained variance based on eigenvalues

Variable	Eigenvalue	Proportion of variance	Cumulative proportion of variance
1	6.45260	0.16131	0.16131
2	4.22889	0.10572	0.26704
3	3.31259	0.08281	0.34985
4	2.74550	0.06864	0.41849
5	1.96879	0.04922	0.46771
6	1.46333	0.04505	0.51276

PCA with a varimax rotation was then conducted on the 40 items of the prototype CS-FA. A KMO measure of sampling adequacy of .71, exceeding the recommended value of 0.6 (Pallant, 2011), and a significant Bartlett's test of Sphericity (2622.16, df=780, p<0.001) was discovered, indicating the use of a PCA for variable reduction was a viable possibility.

As the analysis run on FACTOR indicated that there was little change between components 5 and 6, a PCA was run and restricted to five factors. The rotated component matrix indicated a number of cross factor loadings for 12 items, making the result difficult to interpret. The PCA was re-run and restricted to four factors, which indicated fewer cross-factor loadings. Following guidelines from Pallant (2011), items with communality values below 0.3 were removed, resulting in the removal of seven items (items, 3, 4, 9, 13, 22, 23, and 37). The PCA was run again, and item 43 indicated a communality value below 0.3 and was removed. This resulted in a solution with 32 items which explained 48.5% of the total variance in the data (Table 6.4). The four factors were labelled: Social support; Self-management; Avoidance & Minimisation, and Positive beliefs.

Three items (15, 27 and 28) were found to be negatively loaded in comparison to the rest of these items. During the development of the scale, no items were written to be reverse scored, and there was no rationale to reverse score any items prior to running the PCA. As these three items did not fit the direction of scores of the rest of the items on the sub-scales they loaded on to, they were removed from the scale.

One item (29) loaded onto two factors with factor loadings higher than .40. According to Field (2009), where items load on more than one component, the component containing the highest value should retain that item.

Table 6.4: Factor analysis of the 32-item scale

Social support	**Factor 1**	**Factor 2**	**Factor 3**	**Factor 4**
8. I rely on my Mum or Dad to check food labels for me.	.85			
21. When going out for a meal, I prefer it if somebody else (e.g. Mum or Dad) checks what ingredients are in the food.	.80			
17. I rely on my Mum or Dad to carry my medication for me.	.75			
16. If I want to know more about my FA, I ask somebody (e.g. parents, teachers, friends) for more information.	.75			
20. I ask my Mum or Dad if my food is safe to eat.	.68			
15. If I want to know more about my FA, I find the information myself.	-.57			
36. If I feel worried about my FA, I speak to somebody (e.g. parents, teachers, friends) about it.	.51			
25. If I need to use my adrenaline auto-injector (e.g. EpiPen, JEXT), I prefer someone else to do it for me.	.49			
29. If I feel upset about my FA, I talk to someone close to me about it.	.40			
Self-management				
7. Before eating, I check the food labels to make sure the food is safe for me to eat.		.67		
14. If I'm offered food that I'm unsure about, I read the label or ask about the ingredients, to check if it's safe to eat.		.62		
10. When going out for a meal, I ask what ingredients are in the food.		.59		
11. When I eat at school, I make sure that I'm not near any food that could give me an allergic reaction.		.58		
1. I carry my antihistamines with me in case I have an allergic reaction.		.54		
5. I check that there are no foods around me that I could be allergic to.		.54		
2. I carry my adrenaline auto-injector (e.g. EpiPen, Jext) with me in case I have an allergic reaction.		.52		
42. I am more careful about my FA when I'm in a place that I'm not used to.		.50		
26. I avoid social events (e.g. birthday parties or school trips), because of my FA		.48		
6. I avoid eating with other people, because I worry about having an allergic reaction.		.45		
Avoidance & minimisation				
38. I hide the fact I have a FA from other people, because I don't want them to know about it.			.77	
24. I avoid talking to my friends about my FA.			.68	
39. When I'm with my friends, I'm less careful about my FA because I don't want to be different.			.63	
18. If I feel upset about my FA, I prefer to be by myself.			.53	
12. I won't use my medication if other people are around me.			.58	
28. I tell people about my FA to stay safe.			-.48	
41. I ignore my FA so I can do things with my friends that I normally wouldn't be able to do.			.47	
40. I eat the same foods as my friends, so I don't feel left out, even if I know I'm allergic to it.			.46	
27. I teach my friends about my FA and my medication.			-.47	
Positive beliefs				
35. I look for the positives about my FA to help me feel better.				.76
33. If I'm feeling upset about my FA, I distract myself by doing things that I like.				.70
31. I think to myself, "things could be worse," to feel better about my FA.				.68
32. I compare myself to others, to feel better about my FA.				.66
EIGENVALUES	5.80	4.04	3.08	2.58
VARIANCE EXPLAINED (%)	18.14	12.63	9.64	8.08

Although item 29 loaded higher on component 4, it appeared more suited to component 1 as the coping strategy of the item was aligned to that of social support (seeking emotional support from someone else when upset). I therefore decided to retain item 29 on factor 1.

Reliability analysis was run on the remaining 29 items which indicated a Cronbach's α of .773 with an 'alpha if item deleted' range of .755 and .780 (Table 6.5) indicating high internal reliability with low risk of item redundancy (Pallant, 2011).

Table 6.5: Cronbach's alpha if item deleted - 29-item CS-FA scale

CS-FA items	Cronbach's α if deleted
8. I rely on my Mum or Dad to check food labels for me.	.757
21. When going out for a meal, I prefer it if somebody else (e.g. Mum or Dad) checks what ingredients are in the food.	.761
17. I rely on my Mum or Dad to carry my medication for me.	.763
16. If I want to know more about my FA, I ask somebody (e.g. parents, teachers, friends) for more information.	.755
20. I ask my Mum or Dad if my food is safe to eat.	.756
36. If I feel worried about my FA, I speak to somebody (e.g. parents, teachers, friends) about it.	.755
25. If I need to use my adrenaline auto-injector (e.g. EpiPen, JEXT), I prefer someone else to do it for me.	.764
7. Before eating, I check the food labels to make sure the food is safe for me to eat.	.766
14. If I'm offered food that I'm unsure about, I read the label or ask about the ingredients, to check if it's safe to eat.	.767
10. When going out for a meal, I ask what ingredients are in the food.	.773
11. When I eat at school, I make sure that I'm not near any food that could give me an allergic reaction.	.758
1. I carry my antihistamines with me in case I have an allergic reaction.	.764
5. I check that there are no foods around me that I could be allergic to.	.760
2. I carry my adrenaline auto-injector (e.g. EpiPen, Jext) with me in case I have an allergic reaction.	.765
42. I am more careful about my FA when I'm in a place that I'm not used to.	.762
26. I avoid social events (e.g. birthday parties or school trips), because of my FA	.764
6. I avoid eating with other people, because I worry about having an allergic reaction	.759
38. I hide the fact I have a FA from other people, because I don't want them to know about it.	.772
24. I avoid talking to my friends about my FA.	.774
39. When I'm with my friends, I'm less careful about my FA, because I don't want to be different.	.780
18. If I feel upset about my FA, I prefer to be by myself.	.771
12. I won't use my medication if other people are around me	.771
41. I ignore my FA so I can do things with my friends that I normally wouldn't be able to do	.780
40. I eat the same foods as my friends, so I don't feel left out, even if I know I'm allergic to it	.779
35. I look for positives about my FA to help me feel better	.771
33. If I'm feeling upset about my FA, I distract myself by doing things that I like	.761
32. I compare myself to others, to feel better about my FA	.774
31. I think to myself, "things could be worse," to feel better about my FA.	.761
29. If I feel upset about my FA, I talk to someone close to me about it.	.775

A reliability analysis was then performed for each sub-scale (Table 6.6). The Cronbach's α value for each subscale were as follows: Social Support .84, Self-Management .78, Avoidance and Minimisation .74, Positive Beliefs .75. Although removing item 41 would have increased the overall α value to .78, this would have compromised the α value of the Avoidance and Minimisation sub-scale and so was not removed.

Table 6.6: Cronbach's alpha if deleted for each subscale

Sub-scale	Item	Overall α	Cronbach's α if deleted
Social support	8	.84	.804
	21		.808
	17		.820
	16		.809
	20		.818
	25		.850
	36		.827
	29		.843
Self-management	7	.78	.761
	14		.760
	10		.760
	11		.761
	1		.763
	5		.759
	2		.775
	42		.766
	26		.777
	6		.772
Avoidance and minimisation	38	.74	.656
	24		.703
	39		.691
	18		.738
	12		.734
	41		.729
	40		.729
Positive beliefs	35	.75	.655
	33		.728
	32		.688
	31		.719

Similar to the KidCOPE (Spirito et al., 1998), the 29-item CS-FA (Appendix 41) is interpreted by studying the range of coping strategies used by children and adolescents. For this reason, there are no standardised scores, nor a total scale score calculated. Sub-scale scores are calculated by adding up the values for each question in the sub-scale and dividing this total value by the number of items in that sub-scale to get a mean score ranging from 1-5. There are no reversed items. A higher score represents greater use of that particular coping strategy.

6.3.4. Cross-sectional validity of the 29-item CS-FA

Of the one hundred and fifty-one children and adolescents who participated, one hundred and thirteen children and adolescents completed the CS-FA and the four validation scales. Answers to the subscales of CS-FA were summed and divided by the number of items in each subscale to get mean scores for each subscale.

CS-FA and KidCOPE

There are two versions of the KidCOPE; younger child (ages 8-12) and older child (ages 13-16). The KidCOPE comprises ten coping styles: distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem solving, emotional regulation, wishful thinking, social support and resignation. The descriptive statistics for all subscales can be found in Table 6.7.

Table 6.7: Descriptive statistics for subscales of the KidCOPE

	N	Range	Mean	Standard Deviation	Variance
KidCOPE (young child) N=63					
Distraction	48	2	.85	.714	.510
Social withdrawal	28	2	1.04	.922	.851
Cognitive restructuring	29	2	.83	.658	.433
Self-criticism	14	2	.36	.745	.555
Blaming others	34	2	.97	.717	.514
Problem solving	54	2	1.22	.744	.553
Emotional regulation	46	2	1.11	.706	.499
Wishful thinking	60	2	.58	.696	.484
Social support	48	2	1.42	.613	.376
Resignation	17	2	.24	.562	.316
KidCOPE (older child) N=50					
Distraction	41	4	1.22	1.255	1.576
Social withdrawal	30	4	1.50	1.306	1.707
Cognitive restructuring	37	3	1.22	1.158	1.341
Self-criticism	32	4	1.16	1.505	2.265
Blaming others	36	4	1.42	1.273	1.621
Problem solving	44	4	1.80	1.304	1.701
Emotional regulation	43	4	1.53	1.008	1.017
Wishful thinking	41	4	.44	.976	.952
Social support	46	4	1.91	1.208	1.459
Resignation	38	4	1.32	1.297	1.681

The CS-FA subscale scores were separated according to the age group, with n=60 children (aged 8-12 years old) completing the KidCOPE for young children, and n=53 adolescents (aged 13-16 years old) completing the KidCOPE for older children. Pearson's correlations were run between the subscales of the two measures (Table 6.8).

Table 6.8: Pearson's correlations between CS-FA and KidCOPE

	CS-FA sub-scales			
	Social support	**Self-management**	**Avoidance and minimisation**	**Positive beliefs**
KidCOPE (young child) N=63				
Distraction	.067	-.168	-.115	.141
Social withdrawal	.195	.176	.120	**.527****
Cognitive restructuring	.038	.152	.279	.133
Self-criticism	-.253	.259	-.065	-.158
Blaming others	-.257	.095	.177	.224
Problem solving	-.296	-.021	-.019	**.325***
Emotional regulation	.085	-.036	-.083	.253
Wishful thinking	.039	.142	.024	.046
Social support	.011	-.109	-.231	.137
Resignation	.216	-.348	-.274	-.205
KidCOPE (older child) N=50				
Distraction	-.126	-.042	-.082	.013
Social withdrawal	-.230	.169	-.120	.158
Cognitive restructuring	.163	.131	-.123	.082
Self-criticism	-.047	.157	-.117	.211
Blaming others	-.017	.057	.118	.156
Problem solving	-.126	.056	-.126	.284
Emotional regulation	-.161	.047	.001	.269
Wishful thinking	.024	.157	-.105	-.174
Social support	.**342***	.288	-.154	-.044
Resignation	.160	.256	**-.334***	-.077

*** sig at 0.01 level (2 tailed)*
** sig at 0.05 level (2 tailed)*

Following the guidelines of Pesudovs et al. (2007), it was expected that the constructs of the KidCOPE would significantly correlate with the constructs of the CS-FA as both measures are related in assessing coping strategies. As such, it was expected that coping strategies that have the same or similar functions on both scales would significantly correlate. For example, it was expected that resignation and distraction on the KidCOPE would significantly correlate with avoidance and minimisation on the CS-FA, that social support on both the KidCOPE and CS-FA would significantly correlate with each other, and that cognitive restructuring, wishful thinking and emotional regulation on the KidCOPE would significantly correlate with positive beliefs on the CS-FA.

For children, significant correlations were identified between positive beliefs on the CS-FA, and problem solving (r=.325, p=<0.05) and social withdrawal (r=.527, p=<0.01) on the KidCOPE. This indicates that using problem solving and social withdrawal coping strategies was associated with greater use of positive belief coping strategies. The medium effect size observed between problem-solving and positive beliefs suggests a reasonable relationship between these constructs, whilst the large effect size observed between social withdrawal and positive beliefs suggests a strong relationship between these two constructs.

For adolescents, significant correlations were identified between social support on the CS-FA and social support on the KidCOPE (r= .342, p=<0.05). The medium effect sizes observed that there is a reasonable relationship between these constructs. Avoidance and minimisation on the CS-FA significantly correlated with resignation on the KidCOPE, in a negative direction. Again, a medium sized correlation was observed, which suggests a reasonable relationship between these constructs.

Due to how the KidCOPE is completed, Pearson correlations could only be run for children and adolescents who indicated that they used a particular coping strategy. For children this number ranged from the lowest which was n=17 (resignation) to the highest n=60 (wishful thinking). For adolescents this number ranged from n=30 (social withdrawal) to n=46 (social support). There are therefore correlations for both the KidCOPE child form and KidCOPE teenagers form with medium effect sizes which are not significant due to the small number of participants using these strategies. For example, in the KidCOPE child form, self-management on the CS-FA negatively correlated with resignation on the KidCOPE with a medium effect size (r=-.348). However, only seventeen children indicated that they used resignation as a coping strategy. Therefore, it is likely due to power that this correlation was not significant. Post-hoc calculations using G*power 3.1.9.4 have shown that the power of these calculations ranged from 0.21 to 0.91 for children, and 0.47 to 0.77 for adolescents. Calculating the sample size required on G*Power, to detect significant results I would have needed at least n=109 participants to have used each particular KidCOPE strategy.

CS-FA and RCADS

The RCADS comprises 6 constructs; separation anxiety, generalised anxiety, obsession compulsion, social phobia and depression. The descriptive statistics for all subscales can be found in Table 6.9. Pearson's correlations were run between the sub-scales of the CS-FA and RCADS (Table 6.10). Data was not split according to age group, as there is only one measure that is completed by children and adolescents aged 8-18 years old.

Table 6.9: Descriptive statistics for subscales of the RCADS

	N	Range	Mean	Standard Deviation	Variance
RCADS N=113					
Separation Anxiety	113	19	4.11	3.651	13.328
Generalised Anxiety	113	17	5.53	3.246	10.537
Panic Disorder	113	23	3.55	3.875	15.018
Obsessions/Compulsions	113	13	2.01	2.433	5.920
Major Depression	113	25	4.24	4.632	21.451
Social Phobia	113	24	10.00	5.425	29.429

Table 6.10: Pearson's correlations between CS-FA and RCADS

	CS-FA sub-scales			
	Social support	**Self-management**	**Avoidance and minimisation**	**Positive beliefs**
RCADS N=113				
Separation Anxiety	**.400****	**.285****	-.044	**-.218***
Generalised Anxiety	.101	**.210***	**.239***	.146
Panic Disorder	.026	**.193***	**.273****	-.123
Obsessions/Compulsions	-.19	-.18	-.20	-.15
Major Depression	.135	.144	.099	**-.241***
Social Phobia	.157	.090	**.232***	**-.202***

*** sig at 0.01 level (2 tailed)*
** sig at 0.05 level (2 tailed)*

Studies have shown coping strategies of the CBMC can affect symptoms of anxiety and depression, for example, primary control and secondary control coping strategies are associated with less symptoms of anxiety and depression, whilst disengagement coping is associated with increased symptoms of anxiety and depression (Compas et al. 2012). Therefore, it was expected that using self-management and social support strategies (indicative of primary-control coping) and positive beliefs (indicative of secondary control coping) would be associated with lower symptoms of anxiety and depression, and avoidance and minimisation (indicative of disengagement coping) to be associated with higher symptoms of anxiety and depression. Interestingly, these expectations were not fully met.

Separation anxiety on the RCADS significantly correlated with self-management (r=.400, p=<0.01) and social support (r=.285, p=<0.01) on the CS-FA, and also significantly correlated with positive beliefs with a negative direction (r=-.218, p=<0.05). The positive correlations could suggest that increased use of self-management and social support is a response to experiencing separation anxiety, which did not support our expectations of lower symptoms. However, the small effect size observed between self-management and separation anxiety suggests a weak relationship between these two constructs. In comparison, a medium effect size observed between separation anxiety and social support, suggests a more reasonable relationship between these two constructs. The negative correlation between positive beliefs and separation anxiety could indicate that using positive beliefs (secondary-control coping) as a coping strategy may be associated with lower levels of separation anxiety, an association identified by Compas et al. (2012). However, the small effect size observed suggests a weak relationship between these two constructs.

Generalised anxiety on the RCADS significantly correlated with self-management (r=.210, p=<0.05) and avoidance and minimisation (r=.239, p=<0.05) coping strategies on the CS-FA. These correlations could suggest that experiencing generalised anxiety is associated with increased use of self-management and avoidance and minimisation coping strategies. It is also possible that self-managing FA can cause greater generalised anxiety, or children and adolescents disengage as a result of experiencing generalised

anxiety. However, small effect sizes were observed for both, and suggests a weak relationship for these constructs.

Like generalised anxiety, panic disorder on the RCADS significantly correlated with self-management (r=.210, p=<0.05) and avoidance and minimisation (r=.273, p=<0.01). These correlations suggest that experiencing panic disorder is associated with using self-management or avoidance and minimisation coping strategies. Like that of generalised disorder, self-managing FA may be causing children or adolescents to experience panic disorder, or the experiencing of panic disorder leads to children and adolescents to use avoidance and minimisation coping strategies. However, with the small effect sizes observed, there is a weak relationship between these two constructs.

Finally, social phobia on the RCADS significantly correlated with avoidance and minimisation (r=.273, p=<0.01) and positive beliefs (r=-.202, p=<0.05) on the CS-FA. The positive correlation could suggest that children and adolescents who experience social phobia as a result of their FA, use avoidance and minimisation to cope. It is also possible that social phobia may occur as a result of using avoidance and minimisation strategies. The negative direction of the correlation between social phobia and positive beliefs could suggest that using positive beliefs is associated with decreased social phobia, and does support our expectation of secondary control coping reducing symptoms of this type of anxiety. However, the small effect sizes observed between social phobia and avoidance and minimisation and positive beliefs, suggests a weak relationship between these constructs.

CS-FA and B-IPQ

The B-IPQ comprises eight constructs; consequences, timeline, personal control, treatment control, identity, concern, coherence and emotional representations. Children and adolescents were asked to answer the questions of the B-IPQ based on their FA. Mean scores were computed for each construct of the B-IPQ. The descriptive statistics for all subscales can be found in Table 6.11._ Pearson's correlations were run between the sub-scales of the CS-FA and constructs of the B-IPQ (Table 6.12). Data was not split according to age group, as there is only one measure that is completed by children and adolescents aged 9 years old and upwards.

Table 6.11: Descriptive statistics for the subscales of the B-IPQ

	N	Range	Mean	Standard Deviation	Variance
BIPQ N=113					
Consequences	113	10	6.00	2.619	6.857
Timeline	113	8	9.09	1.766	3.117
Personal control	113	10	5.63	2.729	7.450
Treatment control	113	10	6.73	2.973	8.840
Identity	113	10	6.02	2.478	6.143
Concern	113	10	6.69	2.946	8.680
Coherence	113	8	8.08	1.813	3.288
Emotional representation	113	10	5.16	2.498	6.242

Table 6.12: Pearson's correlations between CS-FA and B-IPQ

	CS-FA sub-scales			
	Social support	**Self-management**	**Avoidance and minimisation**	**Positive beliefs**
B-IPQ N=113				
Consequences	.052	.163	**.214***	.035
Timeline	**-.237***	-.046	.137	.014
Personal control	.049	.-.059	-.040	**.291****
Treatment control	**.199***	.113	.021	.109
Identity	-.122	.067	**.230***	.123
Concern	.076	**.200***	**.322****	.164
Coherence	-.123	.181	-.129	.015
Emotional representation	-.068	.012	**.461****	.026

*** sig at 0.01 level (2 tailed)*
** sig at 0.05 level (2 tailed)*

Illness representations in children and adolescents with FA haven't been widely studied. However, research by Jones et al. (2014) has suggested that adolescents who identified strongly with their FA and had stronger emotional representations of their FA (such as feelings of anxiety, anger and depression), and thus a greater concern for FA, reported greater adherence to self-care behaviours. In adults with FA, Knibb & Horton (2008) found relationships between personal control with greater use of active coping, social support and positive reinterpretation; treatment control with greater use of planning and positive reinterpretation, greater illness coherence with active coping; and timeline with less use of social support. In contrast to Jones et al. (2015), adults with a stronger emotional representation of their FA used less active coping, positive reinterpretation and acceptance coping.

Therefore, it was expected that there would be relationships between identity, emotional representation, personal control, treatment control and concern with social support and self-management on the CS-FA; personal control, treatment control and emotional representation to be associated with positive beliefs; and timeline with social support in a negative direction.

Social support on the CS-FA significantly correlated with timeline (r=-.237, p=<0.05) and treatment control (r=.199, p=<0.05) on the B-IPQ, which met our expectations. A positive correlation with 'treatment control' suggests that belief in the effectiveness of FA medication is associated with using 'social support' as a coping strategy. This could also be possibly related to a greater reliance on parents to administer medication for them if they had a reaction. A negative correlation between social support and timeline could suggest that the belief that FA would continue to last for a long time was associated with reduced use of social support However, small effect sizes were observed, which suggest a weak relationship between these constructs.

Self-management on the CS-FA significantly correlated with concern on the B-IPQ (r=.200, p=<0.05). This suggests that a greater concern for FA was associated with using self-management coping strategies. However, a small effect size suggests that the relationship between these constructs are weak

Avoidance and minimisation on the CS-FA significantly correlated with consequences (r=.214, p=<0.05), identity (r=.230, p=<0.05), concern r=.322, p=<0.01) and emotional representation (r=.461, p=<0.01). These correlations could suggest that the perception of how severely FA affects life, the number of severe symptoms experienced, the greater the concern of FA and how emotionally affected one is by FA, is associated with coping by avoidance and minimisation. Small to medium sized correlations were observed. In particular, the relationship between avoidance and minimisation with consequences and identity is weaker than the relationship between avoidance and minimisation with concern and emotional representation.

Positive beliefs on the CS-FA significantly correlated with personal control (r= .291, p=<0.01), which could suggest that using positive beliefs as a coping strategy, affects how much personal control a child or adolescent has over their FA. However, a small effect size was observed, and therefore suggests that the relationship between these two constructs is weak.

CS-FA and FAIM

The FAIM comprises six questions and with two separate version for children and adolescents; four questions relate to expected outcome (EO) and two are additional independent measure (IM) questions. EO questions capture the perceived expectation of patients of the chance of accidental exposure to an allergen, and the perception of what will happen following exposure. The descriptive statistics for all subscales can be found in Table 6.13.

Table 6.13: Descriptive statistics for the subscales of the FAIM child and teenage forms

	N	Range	Mean	Standard Deviation	Variance
FAIM (child form) N=63					
(How big do you think the chance is that you…)					
Will accidentally eat something to which you are allergic? (EO1)	63	6	3.48	1.435	2.060
Will have a severe reaction if you accidentally eat something to which you are allergic? (EO2)	63	6	5.16	1.588	2.523
Will die if you accidentally eat something to which you are allergic? (EO3)	63	6	3.95	2.011	4.046
Cannot do the right things for your allergic reaction, should you accidentally eat something to which you are allergic? (EO4)	63	6	3.48	1.522	2.318
How many foods are you unable to eat because of your FA? (IM1)	63	5	4.43	1.266	1.604
How much does your FA affect things you do with others? (IM2)	63	6	3.78	1.680	2.821

Table 6.13 (continued)

FAIM (teenage form) N=50					
(How big do you think the chance is that you…)					
Will accidentally eat something to which you are allergic? (EO1)	50	6	3.16	1.218	1.484
Will have a severe reaction if you accidentally eat something to which you are allergic? (EO2)	50	6	5.48	1.129	1.275
Will die if you accidentally eat something to which you are allergic? (EO3)	50	5	4.72	1.400	1.961
Cannot effectively deal with an allergic reaction, should you accidentally eat something to which you are allergic? (EO4)	50	6	2.46	1.054	1.111
How many products must you avoid because of your FA? (IM1)	50	5	3.82	1.101	1.212
How great is the impact of your FA on your social life? (IM2)	50	6	3.26	1.103	1.217

Although to my knowledge, there is no literature on coping and the FAIM, as the FAIM is concerned with management of FA and risk of a reaction it was expected that constructs of the FAIM would significantly correlate with the constructs of the CS-FA to demonstrate disease severity specific to FA. Additionally, the FAIM has been used to measure the construct validity of the FAQLQs and other FA measures such as the Food Allergy Self-Efficacy Scale for Parents (FASE-P) (Knibb, Barnes & Stalker, 2015; van der Velde et al. 2010).

Each subscale of the CS-FA was correlated against each question of the FAIM and split according to age group, with n= 60 children (aged 8-12) completing the FAIM child form, and n=53 adolescents completing the FAIM teenage form (Table 6.14).

For children, significant correlations were identified between self-management on the CS-FA and the chance of having a severe reaction if accidentally eating something to which the child is allergic to (EO2) (r=.320, p=<0.05) and how much FA affects doing things with others (IM2) (r=.315, p=<0.05). This indicates that if a child perceives their chance of having a severe reaction as very high, this was associated with increased use of self-management coping strategies. Similarly, perceiving the impact of FA on what they can do with others as high was also associated with increased use of self-management coping strategies. The medium effect sizes observed between these correlations suggests that there is a reasonable relationship between these constructs.

Avoidance and minimisation on the CS-FA significantly correlated with the number of foods children were unable to eat due to their FA (IM1) (r=-.298, p=<0.05) and the impact of FA on being able to do thing with others (IM2) (r=.251, p=<0.05). The negative correlation between avoidance and minimisation and IM2 indicates that as the number of foods children were unable to eat increase, the

use of avoidance and minimisation coping strategies decreased. The greater the impact of FA on being able to do things with others, was associated with greater use of avoidance and minimisation coping strategies. However, small effect sizes observed between these correlations suggests that there is a weak relationship between these constructs.

Table 6.14: Pearson's correlations between CS-FA and FAIM

	CS-FA sub-scales			
	Social support	**Self-management**	**Avoidance and minimisation**	**Positive beliefs**
FAIM (child form) N=63				
(How big do you think the chance is that you…)				
Will accidentally eat something to which you are allergic? (EO1)	-.176	.149	.131	-.096
Will have a severe reaction if you accidentally eat something to which you are allergic? (EO2)	-.026	**.320***	.174	-.099
Will die if you accidentally eat something to which you are allergic? (EO3)	.036	.216	.199	.056
Cannot do the right things for your allergic reaction, should you accidentally eat something to which you are allergic? (EO4)	-.208	.220	.155	-.361
How many foods are you unable to eat because of your FA? (IM1)	.069	.013	**-.298***	.069
How much does your FA affect things you do with others? (IM2)	.068	**.315***	**.251***	.129
Mean FAIM score	-.060	**.366****	.206	-.077
FAIM (teenage form) N=50				
(How big do you think the chance is that you…)				
Will accidentally eat something to which you are allergic? (EO1)	.004	-.229	.214	-.194
Will have a severe reaction if you accidentally eat something to which you are allergic? (EO2)	-.069	-.075	.232	.066
Will die if you accidentally eat something to which you are allergic? (EO3)	-.168	-.033	**.393****	.074
Cannot effectively deal with an allergic reaction, should you accidentally eat something to which you are allergic? (EO4)	.261	.120	-.084	-.361
How many products must you avoid because of your FA? (IM1)	.122	**.349***	-.190	-.280
How great is the impact of your FA on your social life? (IM2)	.215	**.195***	**.033***	**-.301***
Mean FAIM score	.538	.562	.134	.555

*** sig at 0.01 level (2 tailed)*
** sig at 0.05 level (2 tailed)*

For adolescents, significant correlations were observed between self-management on the CS-FA with the number of foods that had to be avoided (IM1) (r=.349, =<0.05) and the impact of FA on their social life (IM2) (r=.195, p=<0.05). This indicated that as the number of foods that had to be avoided and the impact of FA on social life increased, the use of self-management coping strategies also increased. A medium effect size was observed between self-management and IM1, suggesting a reasonable relationship between these two constructs. However, the small effect size observed between IM2 and self-management, suggests the relationship between these two constructs are weak.

Significant correlations were observed between avoidance and minimisation coping strategies on the CS-FA and perceiving that they were at increased risk of dying if accidentally eating something to which they were allergic to (EO3) (r=.393, p=<0.01) and the impact FA had on their social life (IM2) (r=.033, p=<0.05). These observations suggested that as the perception of dying and the impact on social life increased, the use of avoidance and minimisation strategies also increased. The medium effect size observed between avoidance and minimisation coping and EO3 suggests a reasonable relationship between these two constructs. However, the small effect size observed between avoidance and minimisation and IO2, suggests the relationship between these two constructs are weak.

Finally, a significant, negative correlation was observed between positive beliefs on the CS-FA with the impact of FA on their social life (IM2) (r=-.301, p=<0.05). This could suggest that use of positive beliefs could reduce the impact felt by adolescents of FA on their social life. The medium effect size observed, also indicates a reasonable relationship between these two constructs.

Like that of the KidCOPE, there are several correlations for both the FAIM child form and teenagers form with small and medium effect sizes which are not significant due to the low numbers. For example, small to medium effect sizes were identified between social support on the CS-FA and the belief that one could not effectively deal with an allergic reaction, if consuming an allergenic food (item EO4) on the child and teenage FAIM form, and between social support on the CS-FA with the number of p[products one had to avoid, and the impact of FA on one's social life (items IM1 and IM2) on the FAIM teenage form. However, these effect sizes were not significant. Despite the non-significance, the effect sizes indicate a possible relationship between these subscales of the FAIM with subscales of the CS-FA. Calculating the sample size required on G*Power using post-hoc analysis, to detect significant results I would have needed at least n=109 participants in both age groups to detect significant relationships.

6.4. Discriminative validity of the CS-FA

To assess for discriminative validity, independent samples t-tests were run to determine differences in scores between gender, age group (8-11 and 12-16), allergy type, and hospital attendance following an allergic reaction. One-way analysis of variance (ANOVA) test were run to determine differences in scores between the number of allergies a child or adolescent had and between ethnicities. In addition,

Cohen's *d* and eta-squared (η^2) were calculated to measure the size of an effect in order to understand the extent of the differences found (Cohen, 1992, Levine & Hullet, 2002; Sullivan & Feinn, 2012).

Due to the number of independent samples t-tests and ANOVAs run, and the potential risk of increased Type 1 errors, the family-wise error rate was controlled using the Holm-Bonferroni method (Holm, 1979). This procedure orders the calculated p-values from smallest to largest, and sequentially adjusts the threshold for significance. An alternative is the Bonferroni Correction method, which is another common approach to dealing with multiple comparisons. However, this method has been argued to be too conservative and can decrease the power of the test, unlike the more powerful, sequential version by Holm (1979) (Lindquist & Meija, 2015). The significance value of <0.004 was considered acceptable under the Holm-Bonferroni method for the following tests below.

Gender

An independent samples t-test was conducted to compare the scores of each subscale between genders. There were no significant differences in the scores between gender and the subscales of the CS-FA (Table 6.15). As previously mentioned in section 2.6.6, gender differences in coping has been observed, with boys more likely to use avoidant type coping strategies than girls who have been found to use social support and problem-solving coping strategies (Eschenbeck et al. 2007). Therefore, it was expected that there would be significant differences between genders for the subscales of the CS-FA.

Table 6.15: Independent samples t-test – Gender

	Female (N=50)		**Male (N=63)**				
	M	**SD**	**M**	**SD**	***t*-test**	**p**	***d***
Social support	25.88	7.24	26.54	7.39	.476	.635	-.01
Self-management	33.26	6.77	34.32	4.76	.973	.333	-.18
Avoidance and minimisation	12.96	4.06	13.71	4.29	.950	.344	-.18
Positive beliefs	11.76	3.51	11.59	3.83	.247	.806	.05

Age group

An independent samples t-test was conducted to compare the scores of each subscale between age groups. As mentioned in section 2.6.6, research has shown that younger children can be more dependent on adults for support (DunnGalvin et al. 2009) and may be more like to use distraction coping strategies in comparison than adolescents who are more likely to use problem-solving strategies (Hempel & Petermann, 2005., Zimmer-Gembeck & Skinner, 2011). Therefore, it was expected that there would be significant differences in the subscales of the CS-FA according to age.

Age groups were separated in to 'group 1' (8-11 years old) and 'group 2' (12-16 years old). There was a significant difference in the scores for use of social support between the two age groups, with younger children using more social support than older children. The effect size (d=1.85) was found to exceed Cohen's (1992) convention for a large effect (*d*=.80). There were no further significant differences in the scores for the remaining subscales of the CS-FA (Table 6.16).

Table 6.16: Independent samples t-test – Age group

	8-11 yr olds (N=63)		12-16 yr olds (N=50)				
	M	**SD**	**M**	**SD**	***t*-test**	**p**	***d***
Social support	31.51	5.25	21.60	5.47	9.785	**.001***	1.85
Self-management	39.94	5.53	32.88	5.78	1.928	.056	1.25
Avoidance and minimisation	12.74	4.23	13.95	4.09	-1.547	.125	-.29
Positive beliefs	11.13	3.36	12.13	3.90	1.450	.683	-.27

* considered significant under Holm-Bonferroni (Holm, 1979)

Number of allergies

A one-way between subject's ANOVA was conducted to compare the effect of the number of allergies on the scores of each subscale. The number of allergies were grouped into three categories. "1 allergy", "2 allergies" and "3+ allergies". As described in Chapter 2, to my knowledge, there has yet to be research conducted looking at the associations between number of FA and the impact on coping. However, there has been research that has shown that multiple FA can negatively affect QoL and psychosocial functioning (DunnGalvin et al., 2008; Howe, Franx, Teich & Greenhawt, 2014; Sicherer et al., 2001) which can be associated with the types of coping strategies used (Compas et al. 2012) (See section 2.6.6). Therefore, it was expected that there would be significant differences in the sub-scales of the CS-FA according to the number of FA an individual had. For example, there would be a significant difference in the use of avoidant and minimisation coping strategies between those with three or more allergies and individuals with a single FA.

The one-way between subject's ANOVA showed that there were no significant differences found between number of allergies and subscale scores (Table 6.17).

Table 6.17: One-way between subject's ANOVA – Number of allergies

	Sum of squares	**df**	**Mean Square**	**F**	**p**	η^2
Social support	84.139	2	42.07	.787	.458	.01
Self-management	2.001	2	1.001	.030	.971	.00
Avoidance and minimisation	78.303	2	39.454	2.301	.105	.04
Positive beliefs	43.196	2	21.598	1.612	.204	.03

Hospital attendance following an allergic reaction

An independent samples t-test was conducted to compare the scores of each subscale between those who had attended a hospital following an allergic reaction, and those who did not. As discussed in Chapter 2, to my knowledge, there is yet to be a study looking at the association between coping strategies and hospitalisation following an allergic reaction, although there is evidence that there is an association between hospital attendance and QoL in FA. However, research in studies across different types of chronic illness has suggested that hospital visits can be associated with certain types of coping strategies (See section 2.6.6). For example, asthma studies have shown that use of avoidant coping strategies are

associated with hospital visits, whilst active coping strategies are a protective factor (Adams et al. 2000). Therefore, it was expected that there would be significant differences in the subscales of the CS-FA, depending on whether or not one had attended hospital following an allergic reaction. No significant differences were found between hospital attendance following an allergic reaction and CS-FA subscale scores (Table 6.18).

Table 6.18: Independent samples t-test - Hospital attendance following allergic reaction

	Hospital attendance (N=78)		**No hospital attendance (N=35)**				
	M	**SD**	**M**	**SD**	***t*-test**	**p**	***d***
Social support	26.87	7.09	24.85	7.66	1.362	.176	.27
Self-management	34.48	4.76	32.42	7.34	1.781	.078	.33
Avoidance and minimisation	13.29	4.16	13.57	4.29	.323	.747	-.07
Positive beliefs	11.91	3.81	11.11	3.35	1.064	.290	.22

6.5. Consistency over time of the CS-FA

Time 1:

During the testing of the CS-FA, n=97 children and adolescents opted into be contacted again for the test re-test phase of the CS-FA. Of the participants invited, forty-three children and adolescents participated in the test re-test of the CS-FA completed the CS-FA and FAQLQ at time 1 (Figure 6.1).

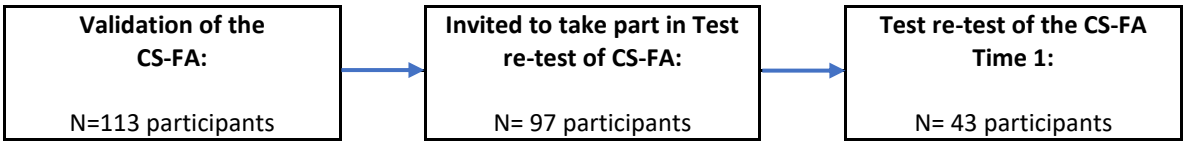

Figure 6.1: Participant flow for Time 1

The sample consisted of n=24 males and n=19 females, a response rate of 45%.The mean age of the sample was 12.47 years old (standard deviation = 2.77) (Table 6.19). Twenty-one children (aged 8-12 years old) completed the FAQLQ-CF, and twenty-two adolescents (aged 13-16 years old) completed the FAQLQ-TF. The participants at Time 1 reflect the original group of participants who completed the CS-FA and validation scales, with a large proportion (>70%) of the respondents at Time 1 identifying as White-British, with smaller percentages associated with the rest of the ethnic groups captured. Similarly, a large proportion of respondents had peanut allergy (>70%), followed closely by 'other nuts' (>40%), and over a third of these respondents indicated that they had 3 or more FA.

Table 6.19: Demographics of participants at T1 and T2

Variable	Summary statistics			
	CS-FA Time 1 (n=43)		CS-FA Time 2 (n = 19)	
Age	Mean	12.47	Mean	12.14
	SD	2.823	SD	2.878
	Min.	8	Min.	8
	Max.	16	Max.	16
Gender	N	%	N	%
Male	24	55.5	10	71.4
Female	19	44.2	4	28.6
Ethnicity	N	%	N	%
White-British	32	74.4	11	78.6
White – Irish	1	2.3	1	7.1
White – other	2	4.6	0	0
Black or Black British – Caribbean	2	4.6	0	0
Black or Black British – African	1	2.3	0	0
Asian or Asian British – Indian	0	0	0	0
Asian or Asian British – Bangladeshi	1	2.3	1	7.1
Asian or Asian British – any other Asian background	0	0	0	0
Chinese	0	0	0	0
Mixed – White and Black Caribbean	1	2.3	0	0
Mixed – White and Black African	0	0	0	0
Mixed – Any other mixed background	3	6.9	1	7.1
Any other ethnic origin group	0	0	0	0
Allergy type	N	%	N	%
Peanut	32	74.4	13	92.9
Other nuts	19	44.1	9	64.3
Egg	9	20.9	4	28.6
Milk	8	18.6	5	35.7
Soya	1	2.3	1	7.1
Fish	4	9.3	2	14.3
Shellfish	6	13.9	3	21.4
Number of allergies	N	%	N	%
1 allergy	12	27.9	4	28.6
2 allergies	14	32.6	2	14.3
3+ allergies	17	39.5	8	57.1

The FAQLQ-CF consists of twenty-four questions across four domains: Allergy avoidance (AA), Risk of accidental exposure (RAE), Emotional Impact (EI) and Dietary restriction (DR). The FAQLQ-TF consists of twenty-three questions across three domains: Allergy avoidance and Dietary restriction (AADR), Risk of accidental exposure (RAE) and Emotional Impact (EI). The descriptive statistics for all subscales can be found in Table 6.20. Cross-sectional validity of the CS-FA was conducted against the FAQLQ-CF and FAQLQ-TF using Pearson's correlation analysis between the subscales of the CS-FA, and the domains and total score of the FAQLQ (Table 6.21). The scoring of the total FAQLQ and domain scores range from 1 "no impairment" to 7 "maximal impairment".

Table 6.20: Descriptive statistics for the subscales of FAQLQ child and teenage forms

	N	Range	Mean	Standard Deviation	Variance
FAQLQ (Child) N=21					
AA	21	5	4.94	1.440	2.075
RAE	21	5	5.29	1.271	1.614
EI	21	5	5.00	1.289	1.661
DR	21	5	4.70	1.452	2.107
FAQLQ (Teenage) N=22					
AADR	22	5	4.57	1.360	1.851
RAE	22	4	4.83	1.487	2.210
EI	22	5	4.72	1.591	2.532

It was expected that maladaptive coping strategies (avoidance and minimisation) would be associated with worsening QoL and poorer scores across the domains of the FAQLQ. These would be indicated through positive correlations with a higher score denoting maximum impairment. Conversely, it was expected that social support, self-management and positive beliefs would be associated with better QoL, with better scores across the domains of the FAQLQ. These would be indicated through negative correlations, with lower scores denoting less impairment.

For children, the results of the analysis suggested that worse QoL (as defined by their total FAQLQ score) was associated with avoidance and minimisation coping strategies, with a positive, large-sized correlation (r=.564, p=<0.01). There were also significant, positive correlations between QoL and using self-management (r=.609, p=<0.01) and social support (r=.451, p=<0.05). It could be that children are experiencing worse QoL due to what is required of them when they self-manage their FA. Additionally, it is also possible that they are requiring more social support because their QoL is poor. The medium to large effect sizes indicate a strong relationship between these constructs and QoL.

The impact of allergen avoidance (AA), risk of accidental exposure (RAE), emotional impact (EI) and dietary restrictions (DR) was also associated with greater use of self-management coping strategies, with mainly large-sized, positive correlations (r=.568, p=<0.01; r=.486, p=<0.05; r=.572, p=<0.01; r=.547, p=<0.05). It is possible that these domains are considered to have maximal impairment on children because of the requirements of self-managing FA. Again, the effect sizes suggest a strong relationship between these constructs.

RAE and EI were also associated with greater use of social support (r=.457, p=<0.05; r=.436, p=<0.05), and could suggest that maximal impairment in these domains requires more social support to cope. Medium effect sizes suggest a moderate relationship between these constructs.

AA, EI and DR were also associated with greater use of avoidance and minimisation with medium to large-sized, positive correlations (r=.540, p=<0.05; r=.349, p=<0.05; r=617, p=<0.01), and could

suggest that level of impairment felt within these domains are due to using avoidance and minimisation coping strategies. The effect sizes demonstrate moderate to strong relationships between these constructs. Positive beliefs did not significantly correlate with any domains of the FAQLQ-CF, nor total FAQLQ score.

Table 6.21: Pearson's correlations between CS-FA and FAQLQ

	CS-FA sub-scales			
	Social support	**Self-management**	**Avoidance and minimisation**	**Positive beliefs**
FAQLQ (Child) N=21				
AA	.346	**.568****	**.540***	-.135
RAE	**.457***	**.486***	.390	-.087
EI	**.436***	**.572****	**.439***	-.177
DR	.410	**.547***	**.617****	-.047
Total FAQLQ	**.451***	**.609****	**.564****	-.125
FAQLQ (Teenage) N=22				
AADR	**.492***	**.650****	.020	-.244
RAE	**.586****	**.563****	-.173	-.216
EI	**.705****	.353	.067	-.266
Total FAQLQ	**.632****	**.568****	-.017	-.262

*** sig at 0.01 level (2 tailed)*
** sig at 0.05 level (2 tailed)*

For adolescents, worse QoL was associated with self-management (r=.568, p=<0.01) and social support (r=.632, p=<0.01) with significant, large sized correlations. The effect sizes demonstrate a strong relationship between these constructs on QoL. Like the results of the analysis with the FAQLQ-CF, these were positive correlations, and could also suggest that like children, adolescents could also be experiencing worse QoL due to what is required of them when they self-manage their FA, and that they may also require more social support because their QoL is poor.

The impact of allergen avoidance and dietary restriction (AADR), RAE and EI was associated with greater use of social support coping strategies with medium to large-sized, positive correlations (r=.492, p=<0.05; r=.586, p=<0.01; r=.705, p=<0.01), and could suggest that the level of impairment felt in these domains requires more social support to cope. The medium to large sized correlations observed suggest a moderate to strong relationship between these constructs.

AADR and RAE was also associated with greater use of self-management with large-sized, positive correlations (r=.650, p=<0.01; r=.563, p=<0.01) and maximal impairment felt in these domains is possibly due to the requirements of adolescents when self-managing FA, particularly where allergen avoidance and risk of an allergic reaction is concerned. The large effect sizes observed also demonstrated a strong relationship between these two constructs. Neither avoidance and minimisation or positive beliefs significantly correlated with the domains of the FAQLQ-TF, nor total FAQLQ score.

Medium to large effect sizes (ranging from .436 to .705) were observed for all significant correlations for both the child and teenage FAQLQ's, which suggests a reasonable relationship between these constructs of the CS-FA and FAQLQ. However, medium effect sizes were observed that were not statistically significant. Indeed, the post-hoc power analysis conducted on G*Power 3.1 shows a power range of 0.58 and 0.68 for children, and 0.66 and 0.97 for teenagers. Caution must be taken due to the small sample size for this analysis, which was also split further due to age, which may have had an effect on the observations shown. It is possible there are further significant correlations that were not found due to low power.

Time 2:

Of the forty-three children and adolescents who completed the CS-FA at time one, nine children and ten adolescents completed the CS-FA at Time 2 (see Figure 6.2). a response rate of 20% of the original 95 participants invited (see Table 6.20 for demographics). Five of those participants had either experienced an allergic reaction, had to see their doctor or attended hospital due to an allergic reaction. Their data was excluded from the intra-class correlations (ICC) analysis, leaving ICC analysis to be conducted on data from 14 participants, a final response rate of 14.7%.

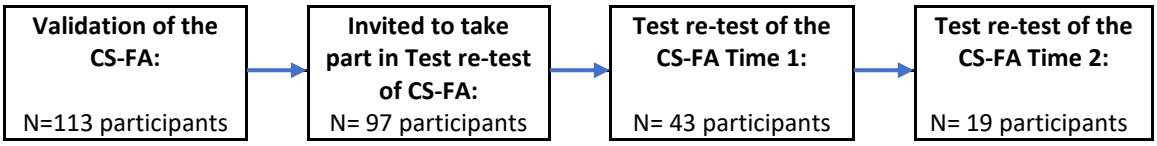

Figure 6.2: Participant flow for Time 2

The participants at Time 2 were slightly less representative of participants at Time 1, with no participants identifying as 'White – other', 'Black or Black British' (Caribbean/Indian/African) or 'Mixed – White and Black Caribbean. Peanut allergy remained the most common allergen type, followed by 'other nuts', and over half of the sample reported having more than 3 allergies. However, these remain similar to the participant demographics of previous UK based studies as mentioned previously in section 6.3.1.

A 2-way mixed effects model ICC (2,1) was conducted, which was deemed the most appropriate for the purpose of the analysis (Shrout & Fleiss, 1979; Koo & Li, 2016). Based on thresholds for ICC categorisation proposed by Koo and Li (2016), there were 'moderate' (0.5>x>0.75), 'good' (0.75>x>0.9) and 'excellent' (x>0.9) ICC scores across all subscales of the CS-FA between Time 1 and Time 2 (Table 6.22).

Table 6.22: Intraclass correlations of the CS-FA

CS-FA Sub-Scales	ICC	95% CI		F	Sig
		Higher	Lower		
Social support	.894	.966	.671	8.997	.001
Self-management	.914	.972	.729	10.888	.001
Avoidance and minimisation	.873	.959	.620	8.108	.001
Positive beliefs	.619	.874	-.102	2.718	.041

In addition, a paired samples t-test run between each subscale at Time 1 and Time 2 showed no significant differences between the mean scores of each subscale at Time 1 and Time 2 (Table 6.23). However, due to the small sample size, a post-hoc analysis was conducted on G*Power 3.1. Results demonstrated that the power ranged from 0.13 to 0.44. It is possible that these statistically significant finding represents a false positive result and that stability over time should be interpreted with caution due to the low number of participants.

Table 6.23: Paired samples t-test between Time 1 and Time 2

	Paired samples t-test				
	M	SD	t	df	p
Social support Time 1 & Time 2	.063	.475	.493	13	.631
Self-management Time 1 & Time 2	-.014	.325	-.164	13	.872
Avoidance and minimisation Time 1 & Time 2	.122	.375	1.221	13	.244
Positive beliefs Time 1 & Time 2	.357	.989	1.351	13	.200

6.6. Discussion

The Coping Scale for Food Allergy (CS-FA) is a coping scale specifically developed for children and adolescents aged eight to sixteen years old with FA. This scale can help to identify the types of strategies children and adolescents are using to cope with their FA and is unique as it has been developed using a CBMC. The scale comprises four subscales which align to the three components of the CBMC (Table 6.24.).

Table 6.24: CSFA subscales and CBMC components

CS-FA	Components of the control-based model of coping
Social Support	Primary control coping
Self-management	Primary control coping
Avoidance and minimisation	Disengagement coping
Positive beliefs	Secondary control coping

The overall scale and each subscale have good reliability, with a Cronbach's α value of at least 0.7 which is considered reliable (Pallant, 2011). The test re-test also demonstrated that the scale has stability over time, with no significant differences in scores identified between time 1 and time 2 in each subscale. However, the results of the re-test should be interpreted with caution due to the small number of participants.

Construct validity

The CS-FA was correlated with the KidCOPE, RCADS, BIPQ, FAIM, and FAQLQ.

For children completing the KidCOPE, only small correlations were identified between the CS-FA subscale 'positive beliefs' with KidCOPE subscales 'social withdrawal' and 'problem solving'. It is possible that children who cope using social withdrawal, may also be using positive belief coping strategies as a way of coping with isolation from others. The association between 'positive beliefs' and 'problem solving' is an interesting observation. The coping strategies within the 'positive beliefs' subscale included strategies that indicate positive interpretation and social comparison. It could be that positive belief coping strategies are also methods of problem-solving for children who are looking for ways to make themselves feel better.

For adolescents completing the KidCOPE, small correlations were identified between 'social support' and the CS-FA sub-scale of 'social support', and between the CS-FA sub-scale of 'avoidance and minimisation' and the KIDCOPE sub-scale 'resignation'. As these constructs in both scales are similar to each other, this is to be expected. However, it is interesting that such a pattern was not identified in children as research has shown that children can have a greater reliance on using social support to cope, particularly from parents (DunnGalvin et al., 2009). This might be because social support scores are universally high in children, leading to a lack of variance, which can have the effect of reducing the correlation.

It could be argued that these results are not unexpected as the KidCOPE measures general coping strategies and not those that are specific to that of FA management and cannot allow for valid comparisons to be made between the impacts of different diseases or conditions (McKenna, 2011). The KidCOPE is also based upon a two-factor model of coping in contrast to the three-factor model of coping that the CS-FA is based upon, which may also explain the number of non-significant correlations. It is also worth noting that when completing the KidCOPE, children and adolescents are asked to think of a scenario that bothered them or caused them stress. Fifty-two percent of participants used a FA scenario, with the remaining 48% using general scenarios such as school, or friendships. This could also explain the mixed validity results, as children and adolescents who did not use a FA scenario in the KidCOPE were thinking of different stressful situations, such as school, which may require different coping strategies. Additionally, the Cronbach's α for the 'younger child' form was .66, below the recommended value of .7 to be considered acceptable and reliable.

Correlations between the CS-FA and RCADS were small to medium-sized and demonstrated the association between anxiety and depression and coping strategies used. Separation anxiety, generalised anxiety, major depression and panic disorder correlated with greater use of social support, self-management and positive beliefs (forms of primary-control and secondary control coping strategies respectively). This supports the findings of previous FA research as anxiety and worries over FA can

lead to a reliance on parents for social support or may promote better adherence to allergen avoidance (Avery et al., 2003; DunnGalvin et al., 2009). Additionally, strategies indicative of primary control coping, such as vigilance, can be a by-product of anxiety (Fenton et al., 2011; LeBovidge et al., 2011), a finding also highlighted in chapters 4 and 5. A review by Compas et al. (2012) described associations between anxiety and depression with the use of primary and secondary control coping strategies. Such strategies were associated with reduced symptoms of anxiety and depression in children and adolescents with Type 1 Diabetes, chronic pain and cancer (Compas et al., 2006; Edgar & Skinner, 2003; Miller et al., 2009; Thomsen et al., 2002).

Higher scores on generalised anxiety and panic disorder also correlated with using avoidance and minimisation – akin to disengagement coping. This again supports the findings of the qualitative results of chapters 4 and 5 where children and adolescents avoided situations that caused anxiety. Previous FA studies have also reported similar findings (Cummings et al., 2010; DunnGalvin et al., 2009), whilst the review by Compas et al. (2012) found associations between disengagement coping and increased symptoms of anxiety and depression for children and adolescents with chronic pain and cancer (Compas et al., 2006; Frank et al., 1997).

Correlations between the CS-FA and B-IPQ were small to medium sized and demonstrated the role FA related illness representations can have on the coping strategies used. Avoidance and minimisation coping strategies was associated with the constructs ‘consequences’, ‘identity’, ‘concern’ and ‘emotional representation’. This indicated that children and adolescents who were greatly affected by FA, experienced more severe symptoms, had greater concern of FA, and were affected by their FA emotionally, used more avoidant and minimisation coping strategies.

Illness representations in children and adolescents with FA haven’t been widely studied, though research by Jones et al. (2014) has suggested that adolescents who identified strongly with their FA and had stronger emotional representations of their FA (such as feelings of anxiety, anger and depression) reported greater adherence to self-care behaviours. This was not identified amongst the current sample, rather a greater emotional representation was associated with increased use of disengagement coping strategies, findings that are similar to a study of adults with FA (Knibb & Horton, 2008). This is possibly due to the different measures used by Jones et al. (2014) where the outcome was adherence and not coping behaviours. Jones et al. (2014) measured adherence using a four-item scale that assessed how often participants carried their AAI and avoided foods, rather than ways adolescents coped. Knibb & Horton (2008) on the other hand used a measure of coping, the COPE Inventory (Carver, Scheier & Weintraub, 1989), to identify the types of coping strategies used which may explain some similarities in the findings with the current study despite the different age group.

Interestingly, the greater number of symptoms (identity) experienced was associated with increased use of avoidance and minimisation coping. FA symptoms can have an impact on many aspects of a child or

adolescent's life, such as their social life (DunnGalvin et al., 2009). Avoidance and minimisation strategies are not unusual, and it is possible that correlations with self-management are not identified if children or adolescents do not feel they yet have the capabilities to manage their symptoms. The chronicity of FA (how long participants thought their FA would last) was associated with reduced use of social support. This could indicate that children and adolescents feel that eventually they must take control of their FA the longer their condition lasts, which supports the findings of the thematic analysis of coping in adolescents in Chapter 5.

One must be mindful of the B-IPQ as a measure used in this study. The Cronbach's α in this study was .66, below the recommended value of .7 to be considered reliable, and French, Schroder & van Oort, (2011) have argued that the B-IPQ does not have 'robust psychometrics', but also state that further developmental work is needed on the B-IPQ. However, a systematic review by Broadbent et al. (2015) has identified that the B-IPQ is a widely used measure, with subscales that are sensitive to change after interventions in randomised controlled trials. Comparable studies in FA where illness representations have been measured (for example, Knibb & Horton, 2008; Jones et al., 2014) have used the IPQ-R, rather than the B-IPQ.

There was mixed evidence for the validity of the CS-FA as correlated with the FAIM. Greater perceived chance of eating allergenic foods was associated with increased use of self-management in children, indicating that children use more self-management techniques to try to avert this from happening. This somewhat reflects the findings of Chapter 4, where children used such strategies to manage their risk, such as asking about food content. Believing that their FA had a greater impact on their life was also associated with self-management coping and reflects the challenges that children experience in having to manage their FA when socialising with others, a finding also reported in chapter 4. Avoidance and minimisation coping were also associated with the impact FA has on socialising with others, which again reflects the findings of chapter 4 and previous research where children can isolate themselves from others if the burden of FA is great. This may explain the association found between this coping strategy and the number of food children cannot eat and may allude to the challenges that children experience when eating out or socialising with others where food is involved, as such events can become sources of anxiety (DunnGalvin et al., 2009). Additionally, Cronbach's α was low for both child and teenage form at .61 and .51 respectively. It may be that each item of the FAIM should be treated separately, rather than using a total FAIM score when conducting such analyses.

Like children, adolescents were found to use self-management coping strategies to manage the impact FA had on their social life, and the number of foods they had to avoid. This supports the findings in chapter 5 where adolescents were found to have increased autonomy when socialising and had to cope with their FA more independently. The use of positive beliefs as a way of coping when believing the impact of FA on socialising to be great was another interesting finding. It is possible that adolescents, despite experiencing challenges when socialising with others, use positive reinterpretation or social

comparisons to cope with this, strategies identified in chapter 5 and in previous research (Fenton et al., 2011; Mackenzie et al., 2009; Marklund et al., 2007).

Avoidance and minimisation coping strategies were associated with the belief of a chance of dying when consuming an allergen, and also with the number of foods that must be avoided. Beliefs around the possibility of death in FA can be associated with anxiety, and research has identified that adolescents who believe that they are at a high risk of death from an allergic reaction, tend to report high FA related anxiety (Herbert, Shemesh & Bender, 2016). Having large numbers of foods that must be avoided adds to the burden of living with FA and can adversely impact the emotional state, such as anxiety, of the patient living with FA (Cummings et al., 2010). These fears and anxieties could explain the use of avoidance and minimisation strategies as a way of maintaining one's safety. Additionally, associations between avoidance and minimisation strategies were also observed with the generalised anxiety subscale of the RCADS.

The CS-FA was also validated with measures of QoL. Use of self-management coping strategies in children were associated with all domains of the FAQLQ-CF, which corroborates findings of FA research that highlight the tasks of self-management of FA that can impact quality of life. However, there were fewer correlations between the rest of the subscales of the CS-FA and the FAQLQ-CF, with positive beliefs not correlating at all. Allergen avoidance and dietary restriction correlated with use of avoidance and minimisation coping strategies. Allergen avoidance and dietary restrictions can be burdensome for children as it can have an impact on different domains of life causing stress and distress. These corroborate the findings in Chapter 4 and across a wide range of previous research (for example, Avery et al., 2003; DunnGalvin et al., 2009.). It was interesting that allergen avoidance did not correlate with social support, however, risk of allergen exposure did. It could be that the perceived risk of exposure is best managed through social support, whilst actual allergen avoidance are strategies that children can actively manage. The association between emotional impact and social support is not surprising with research detailing the use of emotional support in children as a coping strategy to deal with the emotional challenges of FA (Fenton et al., 2011), also indicated in chapter 4.

For adolescents, use of social support coping strategies was associated with all domains of the FAQLQ-TF. The association between emotional impact on QoL and social support coping strategies corroborates the findings of Fenton et al. (2011), which highlights the importance of emotional social support as a coping strategy. Avoidance and minimisation and positive belief coping strategies did not correlate with either subscales of the FAQLQ-TF, nor total quality of life score.

These findings, however, must be interpreted with caution due to the small number of participants completing the QoL scales meaning that this part of the study was underpowered to detect relationships that might exist (Faber & Fonseca, 2014). Despite the mixed results in the validity analyses, it is

important to hold in mind that many coping strategies have more than one function, and no universally effective or ineffective strategy exists.

Discriminative validity

Discriminative validity analysis of the CS-FA only identified one significant difference in the use of social support which was identified between children aged 8-11 and adolescents aged 12-16, with a higher mean score for children. This supports results from previous studies showing that children tend to have a greater dependence on parents than adolescents (DunnGalvin et al., 2009), and supports the findings identified in chapters 4 and 5.

No further statistically significant differences in coping strategies were identified for number of FA or hospital attendance following an allergic reaction.

6.7. Strengths and limitations

A major strength of this study lies in the development of the CS-FA, which followed the guidelines of scale development set out by the FDA (2006), Pesudovs et al. (2007), DeVellis (2017) and Carpenter (2018) and has used primary data from children and adolescents to formulate items for the measure. Although this study faced challenges with recruitment and so was not able to meet the original sample size of at least 300 children and adolescents, analysis indicated that PCA on the prototype CS-FA was considered appropriate with a KMO measure of sampling adequacy exceeding the recommended value of 0.6, a significant Bartlett's test of Sphericity and communality scores of over .3. Without these, PCA would not have been appropriate (Tabachnik & Fidel, 2007; Pallant, 2011).

The coping strategies and subscales of the CS-FA fit the constructs of a CBMC. This was the first time such a model has been used with FA and demonstrates the applicability of this three-factor model of coping with FA. It is interesting that this scale reflects four factors, with two primary control coping factors. Primary control coping encompasses strategies that are managed independently, but also encompasses social support. The division of primary control coping into strategies managed by the self and strategies that are managed through the support of others in the CS-FA, is perhaps indicative of the type of condition that FA is. A condition that whilst can be managed independently, can also require the support of others, particularly for children who will rely heavily on their parents to cope (DunnGalvin et al., 2009).

A wide range of ages completed the CS-FA and validation measures, with children aged 8 to 10 years old making up 40.7% of the total number of participants. With children under the age of 11 underrepresented in FA research, this is a considerable strength of this study. There was also a good split between genders, with males accounting for 55.8% of the total sample.

There are, however, a number of limitations to this study. Firstly, as mentioned, the desired sample size could not be met. Secondly, the majority of participants were recruited via online advertising by Allergy

UK, rather than through secondary care where it would be clear that children and adolescents would have a clinical diagnosis of FA. Though during recruitment, it was made clear that children and adolescents were required to have a clinical diagnosis of FA, we cannot rule out that analysis may have been conducted on those who had been self-diagnosed with FA. Additionally, numbers of children and adolescents who had parents present to read and/or explain questions were not recorded, and therefore any effects of parental presence cannot be determined.

The reliability of the scales used to validate the CS-FA were mixed. Of the subscales used, the KidCOPE, B-IPQ and FAIM demonstrated low Cronbach alpha scores below .7. It is possible that such scales are not suitable for all types of populations and may work best with the population it was originally developed. With the exception of the FAIM, the KidCOPE and B-IPQ can be considered a generic measure. As previously mentioned, generic measures are not designed to capture areas of concern for specific patient population and may include irrelevant items or miss issues specific to the condition, in this case, issues pertaining to FA. However, it is also likely that relationships were not found due to reduced power and a smaller sample size, particularly analyses between the KidCOPE and the FAIM with the CS-FA where the sample had to be split according to age group.

The decision to administer the FAQLQ-CF/TF during the test re-test phase led to results that cannot be fully interpreted due to a smaller than expected sample size for this phase of testing. The decision was made due to concerns over participant burden and whether completing a further scale would have impacted on the number of fully completed measures. Including this alongside the rest of the validation measures may have presented different results that could have more accurately reflect the association between coping strategies and QoL.

Though the test re-test results were encouraging and indicated stability, again, a smaller than expected sample size does make the results difficult to interpret and may be increasing the chances of assuming these results to be true when they in fact may be not, or more likely, missing the identification of relationships that exist between the CS-FA and QoL.

6.8. Future considerations

A confirmatory factor analysis is needed to confirm the sub-scales found in the PCA reported in this study. Additionally, it would be useful to try and obtain a larger sample size to ascertain whether the findings in the validity analyses remain stable or do change. A larger sample size during a test re-test should be considered to fully ascertain if the CS-FA remains a stable measure as indicated in this study.

Additionally, a 35 item CS-FA (29 core items, 6 optional items) may be considered to take too long to complete in clinical settings, and a shorter version of the scale could be developed which may prove valuable in these settings where times can be limited. This could help healthcare practitioners to identify how children and adolescents are coping with their FA, and where they may be struggling.

6.9. Conclusion

In conclusion, the CS-FA is reliable tool to use with children and adolescents with FA, with Cronbach's α values that would be considered reliable. Though results from the validity analyses were mixed, some elements of the CS-FA did correlate with the validation scales used and there is also an argument that coping is a dynamic process that can be dependent on the individual and their circumstances. Further work in confirming the subscales is required with a larger sample size, as there was reduced power which affected some of the validation analyses conducted. In addition, a larger sample could help establish whether validity analyses remain stable or change over time, as the power for this portion of the study was also low. Finally, the CS-FA is also likely to be a useful tool in identifying the coping strategies that are being used by children and adolescents, and where help and support can be given.

CHAPTER 7 General Discussion

7.1. Overview

This chapter summarises the key findings of the work presented in this thesis. It begins with the rationale and aims of this research. I then summarise and discuss how the findings of the empirical work undertaken support or add to existing literature. Theoretical and methodological issues are also addressed, and the implications for healthcare professionals, including recommendations for further research, are outlined. The chapter ends with my final reflections of my journey throughout this research process.

7.2. Introduction and summary of empirical research

There were two key aims of this thesis; the primary aim was to explore and understand how children and adolescents aged 8-16 years old cope with their FA, and a secondary aim which was to develop and validate a FA specific coping instrument for this age group that could be used in clinical and research settings.

The rationale for the work undertaken in this thesis was built upon the need to specifically examine how children and adolescents view the risk of FA and how they cope with the condition. As discussed in Chapter 1, previous research has suggested that the highest proportion of deaths from anaphylaxis occur in adolescence (Bock et al., 2001; Pumphrey & Gowland, 2007) with more recent data also suggesting an increase in food-induced anaphylaxis occurring more rapidly in the peri-adolescent age period and an increase in children attending emergency departments due to anaphylaxis (McWilliam et al., 2018; Motosue et al., 2017). Additionally, the impact of FA on QoL and psychological wellbeing has also been documented. Literature across other chronic conditions has identified the important role of coping in adherence to self-care behaviours, and the association with QoL and psychological wellbeing, yet coping is an area of FA that is under researched despite what is known about the impact FA can have on other factors of an individual's life. Instruments that 'measure' outcomes have been used in chronic illness research and in clinical practice to inform and evaluate treatment, assess functional status and wellbeing, and provide feedback to patients on their progress (Flannery, 2018; Knaup, Koesters, Schoefer, Becker & Puschner, 2009). Coping measures are available for a number of chronic health conditions, however, a measure of coping with FA is not available. In Chapter 2, I presented a rationale for the development of FA specific instrument as a way of identifying and understanding how children and adolescents cope with FA, in favour of a generic measurement of coping that exists.

The lack of clarity on how exactly children and adolescents with FA cope presented an opportunity for this thesis to focus specifically on identifying and understanding coping strategies in children and adolescents with FA, challenge the lack of established models or theory of coping used in FA research

and apply the CBMC, which has been empirically tested with a paediatric population, to provide a clearer understanding of the coping strategies used in this population.

A mixed-methods approach was deemed the most appropriate for this thesis (as discussed in Chapter 2). Additionally, the CBMC (Compas et al., 2001) which has been applied to research with children and adolescents with chronic illness, underpinned the research in this thesis, and helped to inform the analysis and interpretation of coping strategies identified across the qualitative chapters, and informed the development of items of the CS-FA (chapter 6). The definition of coping by Compas et al. (2001) was used throughout this thesis and defines coping as "conscious volitional efforts to regulate emotion, cognition, behaviour, physiology, and the environment in response to stressful events or circumstances" (pg. 89).

The research was divided into four objectives that defined the empirical studies of this thesis:

1. To systematically review literature of coping in children and adolescents with FA (Chapter 3).
2. To explore and identify how children cope with FA and what influences the types of coping strategies used (Chapter 4).
3. To explore and identify how adolescents cope with FA and what influences the types of coping strategies used (Chapter 5).
4. To develop and validate a coping scale for children and adolescents aged 8-16 years old with FA (Chapter 6).

Before embarking on collecting primary data from children and adolescents, it was important to systematically examine the existing FA literature to broaden our understanding of the coping strategies used in this population (Chapter 3). The review synthesised the data of relevant studies which were identified in the search (K=15), using the CBMC to help inform the analysis and interpretation of coping behaviours identified within the narrative of data. Two major issues were identified. First, only three studies including children below the age of 11, meaning there was a lack of data collected from younger children. Second, only two studies had coping as the primary research focus. Therefore, coping strategies had to be identified within the data of research pertaining to different aspects of FA, such as using AAI's, or the experiences of anaphylaxis or being allergic to food. The findings of the review identified that children and adolescents use a variety of coping strategies to cope with their FA, and these strategies can be influenced by a number of factors such as location, or knowledge. However, as the primary focus of the majority of these papers was not on coping, and as coping strategies were having to be drawn from the narrative of papers that had research questions focussing on different aspects of FA, it was not clear how this population, especially younger children, coped with their FA.

Following the systematic review, it was clear that further research was required and so I collected primary data from children and adolescents on coping with FA, continuing to use the CBMC to help inform the analysis and interpretation of data. The objective was to focus solely on strategies used to

cope with FA. An additional objective was to identify and understand the coping strategies used by children below the age of 11 years old, to address the issue of the underrepresentation of children below the age of 11 in FA literature identified in the systematic review.

Analysis of the interview data showed age-related differences regarding the context that coping strategies were used, and this defined the two age groups that were studied; ages 8-11 years old and ages 12-16 years old. For adolescents (Chapter 5), there was a greater focus on the transition to adolescence, such as increased autonomy, moving to secondary school and a new and expanding social group. Such experiences were related to differences in the way adolescents used coping strategies, such as increasing self-management as a result of increased autonomy in situations that may have predominantly been managed by parents in the past. In contrast, children (Chapter 4), had a greater dependence on parents to support them in difficult situations with their FA, however, they did not describe situations of autonomy like their adolescent peers.

Whilst these differences in context were identified, the characteristics of coping strategies remained largely the same across age groups and fit within the constructs of the CBMC as efforts to change a stressor (primary control coping), adapt oneself to a stressor (secondary control coping) or to orient oneself away from the stressor (disengagement coping). For example, both children and adolescents described similar methods of avoiding allergens, such as being vigilant and aware of their surroundings, or using secondary control coping strategies to adapt to the FA and alleviate the impact it had on how FA made them feel. Children and adolescents also described similar types of disengagement coping that related to how they felt others would perceive their FA, such as hiding their condition from others.

Finally, building on the work of the first three empirical studies was the development and validation of a FA coping measure – the CS-FA. In the introduction chapter, I outlined the lack of FA research that studied coping, and the absence of a FA specific coping scale. I presented the case for the development of a FA specific coping instrument versus the use of generic coping instrument in this population. There is a plethora of coping research that includes the use of coping instruments as a way of quantifying coping strategies. Often these instruments can be used in conjunction with other measures, for example, looking at QoL or anxiety and depression, and associations can be made between these outcomes and the types of coping strategies used. The themes and findings from Chapters 3, 4 and 5 informed the development of items of the prototype CS-FA, comprising 49 items (43 core items, 6 optional items – Appendix 23). This was tested on a population of children and adolescents aged 8-16 years old with FA. As discussed in Chapter 6, PCA was used to identify the structure of the scale and produced a solution with four components (‘social support’, ‘self-management’, ‘avoidance and minimisation’, ‘positive beliefs’). These components were found to overlap the constructs of the CBMC which underpinned the research of this thesis (Compas et al., 2001). Following PCA and reliability analyses, this resulted in a 35 item CS-FA (29 core items, 6 optional items – Appendix 41).

The four components of the CS-FA demonstrated good reliability and the CS-FA had good convergent validity with instruments that measured coping, QoL, anxiety and depression, and illness perceptions. Test re-test analyses also demonstrated 'moderate' ($0.5 > x > 0.75$), 'good' ($0.75 > x > 0.9$) and 'excellent' ($x > 0.9$) ICC scores across all subscales, indicating that the CS-FA is a stable measure.

In summary, results of the empirical studies offer novel insights into how children and adolescents cope with FA.

7.3. Characteristics of coping strategies of children and adolescents with food allergy

The introductory chapter of thesis highlighted some fundamental issues within FA research. Firstly, that there is a lack of literature that specifically focuses on coping, and secondly, the absence of a model of coping to understand how children and adolescents with FA cope. The systematic review highlighted a number of studies that indicated the uses of coping strategies, however, only two papers (DunnGalvin et al., 2009; Weiss & Marsac, 2016), specifically focused on coping strategies.

The work presented in this thesis took this research a stage further by adopting the CBMC (Compas et al., 2001) to underpin the findings of this research. By doing so, coping behaviours were categorised within the constructs of the model, and this thesis provides an in-depth analysis of the coping strategies used in the context of this model which has not been done before and adds to existing FA and coping literature.

Using the CBMC as a guide to identify, analyse and interpret the coping strategies within the data of the first three empirical studies, strategies used to cope with FA were identified within the three components of the model. Strategies indicative of primary control coping were those that changed the source of the stressor or minimised risk, strategies indicative of secondary control coping were those that adapted oneself to the stressor, and strategies indicative of disengagement coping were those that removed oneself away from the stressor.

Characteristics of primary control coping

The characteristics of primary control coping strategies found for FA are similar to those identified by Compas et al. (2001, 2012), and include social support, information seeking, and problem solving. In the context of FA, additional primary control coping strategies were identified including avoidance of allergenic foods, vigilance of surroundings and carrying medication, as these strategies could also change the source of the stressor and minimise risk. These behaviours were reported in my systematic review (Gallagher et al., 2012; Mackenzie et al., 2009; Sommer et al., 2014), and were again found in both children and adolescents in the interviews discussed in Chapters 4 and 5.

Social support was used by both children and adolescents, and in this thesis, two strands of social support were identified in the interviews; practical and emotional support. Children had a greater dependence

on the support of parents to cope with their FA on a day to day basis, corroborating the findings of DunnGalvin et al. (2009) and Fenton et al. (2011). Among adolescents, there was reduction in the dependence on parents for practical support, which is similar to findings of developmental coping research by Zimmer-Gembeck and Skinner (2011).

Though FA literature has highlighted the important role parents play in providing support for FA management (DunnGalvin et al., 2009; Fenton et al., 2011; Macadam et al., 2012), interview data (Chapters 4 and 5) provided additional insight into other sources of support used by children and adolescents not previously identified; siblings with FA, and HCP's such as counsellors. These findings contribute to our understanding of the support networks used by children and adolescents with FA that extends beyond the role of parents and medical professionals, such as allergists or nurses.

Previous research has compared areas such as QoL between children with FA and their healthy siblings, or the roles that non-FA siblings have. For example, King, Knibb & O'Hourihane (2009), found that QoL and anxiety scores in children with peanut allergy could be worse than their siblings, whilst a study by Stensgaard, Bindslev-Jensen & Nielsen (2017) found that siblings were protective and had concerns for the wellbeing of their FA adolescent sibling. However, to the best of my knowledge, no study has yet to provide insight into the roles of siblings who have FA themselves in providing support. In the interviews I conducted, both children and adolescents described seeking practical and emotional support from their siblings with FA, including advice on living with a FA as they grow up, which has not been reflected in FA literature to date. It therefore seems that siblings with FA are in a unique position to provide support that results from the shared experience of FA that others such as parents, siblings or friends without FA would not be able to provide. This might explain why siblings without FA were not mentioned as a source of support. However, it is unlikely that siblings without FA are not able to provide their own form of support as Stensgaard et al. (2017) found that siblings without FA had acquired the knowledge and experience to support their sibling with FA through living with their sibling over a number of years.

Though only reported by a handful of children and adolescents in my interviews, the identification of counsellors providing support was particularly salient, as it demonstrated that children and adolescents will reach out for psychological support if this is accessible to them. An RCT by Scholten, Willemen, Last, Maurice-Stam, van Dijk-Lokkart et al. (2013) identified the positive impact that psychosocial support can have on coping in children with chronic illnesses, and this was further illustrated by a child in one of my interviews who commented on how such support helped him to manage the worries he had related to his FA. But the limited data pertaining to psychological support or the support provided by counsellors both in this thesis and in the wider FA literature in children and adolescents, is telling of the limited availability of psychological support dedicated to patients with FA. This was discussed by one adolescent, Natalie (Chapter 5) who described the challenges she had in accessing psychological support.

True to its categorisation as a primary control coping strategy, information seeking helped children and adolescents manage an FA stressor, as it equipped them with the information needed to act upon any potential risk or to make safe choices regarding the food they ate and where they could dine. Whilst label reading is one way of seeking information, previous FA literature has highlighted the challenges with such a method, as labels can sometimes be unclear regarding the presence of allergens (Mackenzie et al., 2009). This is further supported by my findings in Chapters 4 and 5, particularly around trace-labelled foods which could add confusion due to its lack of clarity.

There were, however, findings related to information seeking that to the best of my knowledge have not been identified in FA literature before. Both children and adolescents described using the Internet as a resource to seek FA information. Using the Internet to seek information about one's health has been identified in adolescents before (Radovic et al., 2018; Rhee, Wyatt & Wentzel, 2006). In my interviews, differences between how technology was used was identified between the two age groups. Adolescents used the internet on their mobile phones when socialising with friends, which supported them to make safe choices with where they would eat by searching for menu's beforehand or looking for restaurants that could cater for their needs. Children also used the Internet as a tool to enhance their learning or to watch videos about how to use their AAI, a finding not previously identified. Whilst it is of course possible that children and adolescents were potentially accessing websites that may not have contained accurate information, and that Internet use in children may have been facilitated and supervised by a parent, this finding is important to note as it demonstrates the different ways children and adolescents seek information as a way of coping and offers the possibility of online interventions.

Carrying medication was a coping strategy that was used to minimise the risk of not being able to treat an allergic reaction. Both children and adolescents recognised the importance of carrying medication, however, problems associated with carrying AAI's were identified, supporting the findings of previous literature which has expressed the physical challenges of carrying AAI's stemming from the size and shape of the device (Akeson et al., 2007; Gallagher et al., 2011). Previous literature has underreported on AAI use in children, and my systematic review identified only papers relating to AAI use in adolescents aged 12-19 years old. However, the findings from my interviews showed that in some circumstances children carried their AAIs with them, for example, if visiting a friend's home, rather than always relying on parents to carry the AAI for them. It also identified that children had similar feelings to their adolescent peers regarding the shape and size of their AAI. Coping strategies to facilitate being able to carry an AAI, such as packing medication separately or leaving notes to remind them to carry their medication with them was identified in both children and adolescents, demonstrating the use of problem-solving to make this process easier. These strategies have not been identified in previous research.

Characteristics of secondary control coping

Examples of secondary control coping were found in my systematic review and interviews and were used by children and adolescents to help them adapt to the FA stressor. These included positive reinterpretation, acceptance and distraction, and served as a way of managing emotional arousal.

Using positive reinterpretation as a coping strategy could help children and adolescents frame the challenging or negative aspects of their FA more positively. My systematic review included a study by Macadam et al (2012) who reported that adolescents used this way of thinking to balance negative feelings against the perceived advantages of having an AAI on them. Both children and adolescents in my interviews had similar narratives and descriptions of balancing the negative with the positive and would focus on the importance of carrying medication even if it were burdensome, or they would focus on the foods or activities that they could enjoy rather than those that they could not. The identification of such a coping strategy in this thesis in children supports the findings by Skinner and Zimmer-Gembeck (2007) who have identified that children can modulate emotional states through positive self-talk and cognitive reframing. This contradicts earlier research that suggested that children did not have the same cognitive resources as adolescents to employ such strategies (Weisz et al., 1994). What is unknown, however, is the role parents might in play in influencing the use of these coping strategies. If indeed children do not necessarily have the cognitive resources to use these strategies, it is perhaps the parents who may be using such statements and children then adopting these statements.

Whilst acceptance is a secondary control coping strategy, I found limited use of this coping strategy in children and adolescents with FA. For adolescents, using acceptance appeared to be associated with the duration of the FA diagnosis. Those who had been diagnosed as a child stated that they were now 'used to it' compared to one adolescent who had been diagnosed recently and found it harder to adjust to the changes needed to manage their FA safely. Previous research has identified a link between acceptance and better self-management and adaptation in adolescents with T1D (Jaser et al., 2012), and so it may be useful to encourage acceptance when children and adolescents are diagnosed with FA as a way of managing their condition.

The use of downward social comparisons and hierarchies of FA or illness discussed by children and adolescents in my interviews is a novel contribution to secondary control coping strategies. To my knowledge, such strategies have not been identified as a type of secondary control coping by Compas et al. (2012). However, such methods were found to help children and adolescents adapt to the stress of their FA, which is a characteristic of secondary control coping, and so adds to the model and type of strategies that fall within this category. My findings also support previous research by Marklund et al. (2007) and Mackenzie et al. (2009) where adolescents made comparisons of their own FA with other types of FA. Adolescents in my interviews described a FA hierarchy, where other types of FA were considered to be more severe or worse than their own. This hierarchy was previously identified by Macadam et al. (2012) However, a unique finding that contributes to FA literature, is the use of

downward social comparisons that I identified as being used by children. Downward social comparisons were not only made with children with other types of FA, but also with other types of chronic conditions and both an FA and illness hierarchy were identified in the 8 to 11-year olds. To my knowledge, this has not been reported in children with FA, although such a coping strategy has been identified in children with cystic fibrosis (Ernst, Johnson & Stark. 2010; Pfeffer, Pfeffer & Hodson, 2003). The identification of this form of coping contributes to existing literature as it demonstrates that children have the cognitive ability to make such comparisons and recognise their own health status in the context of others. Similar to positive reinterpretation, it is not known how children and adolescents learn to make such comparisons, and whether this is a coping strategy that is facilitated by parents or other adults who may use such comparison statements in their conversations with their children.

Distraction is considered a secondary control coping strategy as this form of coping decreases emotional arousal (Connor-Smith et al., 2000). However, using distraction as a coping strategy was only identified by two children in my interviews, and was not identified in any of my interviews with adolescents or from the studies included in the systematic review. Distraction coping strategies could be self-managed or facilitated by parents. For example, in my interviews, one child described watching videos to take her mind off things whilst another described how her mother would take her out for the day. Zimmer-Gembeck and Skinner (2011) posit that children may actually use distraction, but only begin to intentionally deploy this as a coping strategy in later childhood. My systematic review and interviews did not identify the use of this by adolescents, and so this type of coping in this age group warrants further investigation.

Characteristics of disengagement coping

The characteristics of disengagement coping strategies identified in this thesis, were those that orientated the individual away from the FA stressor, such as avoidance of social situations that were deemed high risk or avoidance of disclosing or discussing FA with others, which supports the definition of disengagement coping by Compas et al. (2001).

In my interviews children and adolescents demonstrated coping by avoidance, particularly in situations that they considered to be high-risk and posed a risk to their health. Situations that saw the use of disengagement coping were largely similar to those identified in my systematic review and included restaurants, school and social events such as birthday parties (DunnGalvin et al., 2009; Fenton et al., 2011; Gallagher et al., 2012; Stjerna, 2015). In my interviews, avoidance coping was demonstrated by children and adolescents either removing themselves from a situation or location that they felt was high-risk, but also from a situation where they felt they had no control. For example, adolescents expressed uncertainty in secondary schools as friends and peers could bring in their own lunches. This contrasted with children where the school provided the lunches, which helped the child feel some level of control over food. For one child, total avoidance of eating outside of the home, such as at restaurants and

birthday parties, stemmed from the perception her parents had of the risk and danger of eating outside of the home. Parental perceptions of threat, and consequent anxiety, can have an impact on the way children themselves perceive risk (DunnGalvin et al., 2009). Therefore, avoidance of locations as a coping strategy may be partially influenced by parental perceptions of risk and danger, and how this is modelled to the child.

Avoidance was not just a physical concept, but also took the form of orienting the child and adolescents away from discussing FA with others. A striking finding was the concerns of the impact FA could have on social relationships and self-identity. Deliberately not talking about FA is a coping strategy identified by DunnGalvin et al. (2009), and both children and adolescents in my interviews demonstrated this behaviour as a way to avoid feeling uncomfortable about their FA, or to avoid potentially being judged by their friends and peers. I also found that adolescents avoided discussing or disclosing their FA with restaurant staff. Both children and adolescents also minimised the presence of FA, such as hiding their FA or medication from others. Although the feeling of being different to friends and peers is commonly viewed as negative and is often identified in adolescents with FA (Akeson et al., 2007; DunnGalvin et al., 2009; Marklund et al., 2007), my interviews with children highlighted that identity issues are also pertinent in a younger age group and children will use strategies that diminish the presence of FA, such as hiding their medication from others, in order to appear healthier and more like their friends and peers.

7.4. Determinants of coping strategies in children and adolescents with Food allergy

Whilst the CBMC helped to identify and interpret the coping strategies used by children and adolescents with FA, and where these coping strategies fit within the three constructs of the model, it is important to understand the uses behind these coping strategies. The findings of this thesis illustrated a number of determinants that could influence how and what coping strategies were being used, and these are discussed in the following sections.

7.4.1. Age

Developmental work into coping by Zimmer-Gembeck and Skinner (2011), Hampel (2007) and Hampel and Peterman (2005) have shown how ways of coping can differ by age. In my systematic review, children below the age of 11 were underrepresented, and although the findings suggested that children sought more support from parents to cope, there was not enough data from children below the age of 11 to fully understand how they coped with FA and if there were differences in the way they coped in comparison to adolescents. The interviews I conducted with children and adolescents showed that whilst the types of coping strategies used were largely the same, some age-related differences were identified. These differences were not only specific to the types of coping strategies used, but also the contexts these strategies were used in and how the responsibility of FA was viewed.

For example, children reported greater use of parental social support as a coping strategy compared with adolescents. From the narratives given by the adolescents I interviewed, their social experiences changed, both at school and outside of the home. Having increased autonomy at school and outside of the home, influenced more independent management of FA and self-reliance. On the other hand, children were yet to experience the same level of autonomy as their adolescent counterparts and were still largely in the company of their parents, and this difference was evidenced by their descriptions of seeking and using social support, particularly from parents, as a coping strategy. The results of the discriminative validity analysis of the CS-FA (chapter 6), also identified significant differences identified between children (aged 8-11 years old) and adolescents (aged 12-16) in the uses of social support. These findings also reflected the developmental work by Zimmer-Gembeck and Skinner (2011) who described age trends associated with coping such as seeking social support, where there is a move from a reliance on adults to more self-reliance with age.

A change in the social experiences of adolescents, that differed to those of the children interviewed, acted as a drive for more independent coping and self-management. In addition to increasing self-reliance/decreasing social support, was the adoption of primary control coping strategies that would have been used by parents, for example, asking for the allergen menu or informing staff about their FA when eating outside of the home. Adolescents also took more responsibility for their AAI both in school and outside the home, in contrast to children who did not have the same level of responsibility. Quotes by Alice and Amelia (Chapter 5) highlighted the change in how the responsibility of FA is perceived as one gets older and shifts from the parent to the adolescent. In addition to the reduced parental oversight and increased autonomy for adolescents, the expectation of needing to take responsibility and ownership for one's FA, may also influence the drive for self-management and independent coping during this age. Contrasting the thematic maps between the qualitative studies (Chapters 4 and 5), primary control coping strategies used by adolescents were more focused on independent and active coping strategies, tying in with the increased autonomy and independence experienced by this age group. Indeed, these changes were focused within the themes where adolescents described instances of increased independence, such as at secondary school or whilst socialising with friends outside of the home. In contrast, social support, in particular by parents, played a large role in the primary control coping strategies used by children to cope with FA.

Whilst these differences in independent coping and use of social support were observed, some children described independently carrying their medication, or informing staff about their FA, whilst some adolescents described relying on their parents for support. And again, this could be seen in the thematic maps of these two chapters. The school environment demonstrated that children, like adolescents, were independently managing their FA, for example, by checking their environment or the content of their friend's food. Additionally, the children I interviewed demonstrated the use of secondary control coping strategies, like the adolescents, for very similar issues pertaining to identity which again can be seen on

the thematic maps of both chapters. The use of secondary control coping in children contrasts with the results of earlier work by Weisz et al. (1994) who suggested that children do not have the cognitive resources to utilise such strategies.

Nonetheless, the findings within this thesis do indicate that in terms of coping strategies, there can be differences influenced by the experiences associated with age. As children will be in the company of their parents more so than adolescents, greater use of social support as a coping strategy in this group should be expected. However, it should not be assumed that children or adolescents will cope in certain ways due to their age, as demonstrated by the mixed use of coping strategies in both age groups, with the need of parental support still evident for adolescents, and more independent and active coping in children.

7.4.2. Gender

Previous research (Eschenbeck et al., 2007; Jaser et al., 2011) has highlighted that there can be differences between the way's boys and girls cope. For example, boys have been found to use more avoidant or distraction strategies, in comparison to girls who have been found use more primary control coping strategies, such as social support or problem-solving strategies.

The qualitative studies in my systematic review, such as Gallagher et al. (2011), alluded to the challenges experienced by boys who appeared to report more difficulties with carrying their AAI than girls. In the interviews I conducted with children and adolescents, the same difficulties associated with carrying an AAI were also identified in male participants, but not mentioned by any of the girls interviewed.

The difficulty experienced with carrying AAI's for boys appeared to be more prevalent when socialising outside of the home, for example, when visiting a friend's home or going into town with friends. When socialising outside of the home, with the exception of one boy in Chapter 4 who had a 'bum bag' to carry his AAI in, boys in both Chapters 4 and 5 did not carry a bag with them that they could then use to carry their AAI. In comparison, all of the girls in Chapter 5 described taking a small bag with them if going into town. One boy, Adam (Chapter 5), felt that it was not the norm for boys to carry bags with them. It is possible that the gender stereotype associated with carrying bags could be a contributing factor to the challenges with carrying medication for boys. The exception to this was school. Whilst it could be burdensome to carry medication in addition to what is needed at school, carrying medication at school was not a problem for boys as they were able to put their AAI in the school bag.

Adolescent boys in Chapter 5 described uses of disengagement coping with regards to a FA identity more so than girls, such as supressing their FA by concealing their AAI or not disclosing their condition to friends or peers. As previously explained by Williams et al. (2000), boys can find signs of illness as potentially stigmatising, and it is possible that the boys I interviewed felt that there was more negative stigma attached with the FA in comparison to girls; although concerns over a FA identity, and how it would be perceived by others was expressed by both girls and boys.

Although there were challenges and strategies that were more prevalent in boys than girls, such as carrying an AAI or using disengagement coping strategies with regards to their FA identity, looking more broadly into findings of the qualitative studies found, both boys and girls described a wide range of primary control, secondary control and disengagement coping strategies. This was also supported by the findings in Chapter 6, where discriminative validity analysis of the CS-FA showed no significant gender differences between the coping strategies used. In fact, contrary to what previous research has suggested regarding the types of coping strategies used, there were examples of boys seeking social support, whether this was from parents, friends or professionals, and girls using avoidant coping strategies, such as eating lunch away from friends as a way of avoiding the possibility of an allergic reaction. Additionally, research into risk taking and coping strategies of adolescents and young adults with FA by Sampson et al. (2006) found that those categorised as 'high risk' as they coped by not always carrying an AAI and ate allergenic foods, could not be distinguishable by gender. Whilst no significant differences were identified between boys and girls in the ways they coped, it is possible that the expectations and stereotypes associated with each gender, can influence the coping strategies used.

7.4.3. Location

How location could influence the types of coping strategies used was first highlighted in my systematic review. Findings from the review identified that children and adolescents dichotomised places to be high-risk, such as restaurants, or low risk such as the home (DunnGalvin et al., 2009), and coping strategies would differ. The findings from the interviews I conducted with children and adolescents and the ways in which they coped with their FA in different locations, were congruent with the findings of my systematic review, and children and adolescents expressed similar high and low risk locations.

The systematic review identified that adolescents adjusted their approach to allergen avoidance depending on the location they were in (Stjerna, 2015), and this was demonstrated by both children and adolescents in the individual interviews. For example, some children and adolescents would take fewer precautions with their FA when in a familiar location, such as leaving their medication at home, similar to the findings by Gallagher et al. (2011), Macadem et al. (2012) and Stensgaard et al. (2017). When in high-risk locations such as restaurants and schools, some children and adolescents that I interviewed reported using primary control coping strategies, such as enquiring about food content and being vigilant of their surroundings, similar to the findings identified by DunnGalvin et al. (2009) and Stjerna (2015). In addition, disengagement coping strategies were also reported, such as avoiding eating with friends at school, or refraining from eating out in public at all, like those reported by DunnGalvin et al. (2009) and Macadem et al. (2012).

There was variation in coping responses by children and adolescents in high-risk locations, such as at restaurants and schools. Some acted upon the risk and took precautions and independently coped with their FA, whilst others deferred responsibility for coping with FA to their parents or avoided certain

locations altogether. In low-risk places such as the home, there was an assumption that home was allergen free and there was a lack of variation in responses as there was a reliance on parents to provide an allergen free home.

As first mentioned in the introductory chapter of this thesis, perceived and actual controllability of a stressor may be crucial in our understanding of how children and adolescents cope with health and illness related stressors (Compas et al., 2012). When considering the role of location in influencing the way children and adolescents with FA cope, it may not only be what a location means to a child or adolescent, and whether a location is considered high or low risk, but also how much control a child or adolescent feels they have in the location that they're in. For example, the preparation of food in restaurants or the packed lunches of other children taken to school, is not within the control of the parents or the child or adolescent with FA. In contrast, at home, food is completely controlled by the parent. As was highlighted in the systematic review, such locations could be unpredictable and cause stress if there was a lack of awareness amongst staff or other people (DunnGalvin et al., 2009; Stjerna, 2015). Interestingly, in a high-risk yet familiar location, the perception of controllability can increase, and this was identified in Chapter 5, where familiarity equated to control and safety. However, the perception of controllability can be disrupted as described by Mike (Chapter 4) when his usual dish was no longer being served. This demonstrates the fragility of the safety and trust that has to be built by children and adolescents with FA, but also suggests that it is the changes experienced in a location, rather than location itself, that can be problematic.

The experiences an individual has had in a certain location could also influence the coping strategies used. For example, Christopher (Chapter 4) spoke of having an allergic reaction at school. As a result, Christopher described having daily worries about his FA when at school and would cope with these worries by constantly checking if he was experiencing symptoms of an allergic reaction as a way of alleviating the worries. On the other hand, having a positive experience, such as finding safe foods/restaurants, saw individuals such as Elliot (Chapter 4) and Harry (Chapter 5) ordering the same food, or eating at the same restaurant. Therefore, it may not just be controllability, or the perception of risk associated with a location, but also the experiences one has that determines coping responses.

It is also possible that the perception parents have of certain locations, may influence the coping responses of their child. For example, Jasmine (Chapter 4) described feeling safe at home because "it won't have food there that will make me react". But in contrast, would not eat outside of the home or attend social events like birthday parties, and did not feel safe doing so because her parents felt that it was unsafe. It is possible that Jasmine's parents did not feel confident in managing her FA safely if she was eating outside of the home, which also influenced her own perception of safety. How much protection a parent places on their child could affect how their child copes later on (Power, 2008).

Whilst certain locations will carry greater risk than others, the mixed findings in the ways both children and adolescents coped with their FA in these locations suggests that in addition to risk, other factors, such as controllability, experience and parental influence of such a location may also influence the coping strategies used.

7.4.4. Duration of food allergy diagnosis

In my systematic review, being able to normalise and manage FA was associated with the duration of FA diagnosis, as those who had being diagnosed later in childhood had a shorter amount of time to come to terms with their condition (Mackenzie et al., 2009). Of the children and adolescents I interviewed, only one participant had a late diagnosis of FA at the age of 16, with the rest of the participants being diagnosed in early childhood. However, distinctions could be made between Helen's experience of a later diagnosis (Chapter 5), and the participants, both children and adolescents, who had been diagnosed earlier, as her experience and narrative starkly contrasted the rest of the participants. In terms of acceptance of her diagnosis, there were descriptions of a yearning for her 'pre-FA' life, and the use of disengagement coping strategies as she didn't feel she was yet able to safely eat outside of the home with her friends. In contrast, the narrative of participants diagnosed in early childhood in both chapters 4 and 5 was that of more acceptance of the FA that they were living with as it had become a part of their life, their 'normal'. These views echoed the findings of the study by Mackenzie et al. (2009).

In addition to the acceptance associated with the duration of diagnosis, my systematic review also found that an early diagnosis of FA was associated with certain coping strategies. Mackenzie et al. (2009) identified that adolescents with a recent diagnosis used coping strategies driven by anxiety, such as hyper-vigilance, or disengagement coping, such as denial. Duration of diagnosis can also affect knowledge, and asthma studies have shown that patients with a longer duration of diagnosis of asthma have better knowledge of their condition (Sharifi, Pourpak, Heidarnazhad, Bokaie & Moin, 2011). It was telling that in addition to the challenges with accepting a FA diagnosis, Helen did not feel confident in being able to safely manage her new diagnosis.

Being diagnosed with a chronic health condition in later life can be challenging, as age appropriate transitions need to be navigated in addition to the increasing responsibility for their health condition (Monaghan, Helgeson & Wiebe, 2015). As found in the study by Mackenzie et al. (2009), adolescents diagnosed with FA later, were having to learn how to manage their condition very quickly. A diagnosis during later childhood or in adolescence could therefore present a disruption to the important changes experienced during this time with schooling, relationships, social life and self-identity (Turner-Cobb, 2014). The duration that a child or adolescent has been diagnosed with FA could therefore have a wider impact, not only affecting how individuals accept and perceive the condition and how it fits within their self and identity, but also how much they know, understand and manage the condition. Therefore, it is likely that the experiences and knowledge that come from living with FA for a longer duration is yet to

be experienced by individuals with a later diagnosis of FA such as Helen and could affect the coping strategies used as highlighted by Mackenzie et al. (2009).

7.4.5. Food allergy knowledge and education

An interesting finding to emerge from the systematic review and the qualitative chapters of this thesis was the importance of knowledge in how children and adolescents coped with their FA. In the systematic review, knowledge was key in being able to use an AAI for adolescents, and could affect whether the device was used correctly, and administered at the correct point of an allergic reaction taking place (Gallagher et al., 2011; Gallagher et al., 2012, Jones et al., 2015).

In the individual interviews I conducted, children demonstrated variability in what they knew and understood about their FA, particularly around AAIs and trace-labelled products. This variability was also identified within this group, with older children (aged 10 and 11) having a better understanding of trace labelled foods than younger children (aged 8 and 9). A lack of understanding or knowledge in these two areas saw children cope in two different ways, by either deferring to their parents for support or seeking further information for themselves. Interestingly, the issue of knowledge was not discussed by the adolescents I interviewed, and this perhaps demonstrates that FA knowledge increases with time. However, it is also possible that the adolescents interviewed think that they, for example, know how to correctly use an AAI. However, as the findings by Gallagher et al. (2011) and Gallagher et al. (2012) indicates, there may be inconsistencies or deficiencies in knowledge that were not identified during the interviews.

How much children and adolescents know and understand about their condition can affect how well they manage their FA and the type of coping strategies they use. This has been discussed across other chronic diseases. For example, Moradkhani, Kerwin, Dudley-Brown & Tabibian (2011), found a significant, positive association between greater irritable bowel knowledge and the use of adaptive coping strategies. Adolescents with greater disease knowledge of sickle cell disease perceived greater treatment control for the condition (Asnani, Barton-Gooden, Grindley & Knight-Madden, 2017). This highlights the importance of good FA education to support the development of FA knowledge. As was identified in my interviews with children, the Internet could be a useful source of knowledge when researching how to use an AAI, as well as attending allergy support groups to share ideas on self-management skills. Peer education has been expressed as a preferred method of education by some adolescents (Monks et al., 2010).

As mentioned in Chapter 4, repeated education is important (Taddeo et al., 2008) and may be required during childhood in order to grasp and understand FA and how to treat it, and to facilitate more independent use of primary-control coping strategies when it comes to coping with FA. Having repeated education may go on to influence how adolescents with FA cope, particularly if the way they are taught and how much they know about their FA at an early age, shapes their understanding and coping

strategies for the future. FA education could be tailored to developmental stages, for example, when children are transitioning to primary school, or when adolescents leave home to attend university.

7.5. Contribution to theory

This thesis was informed by the CBMC (Compas et al., 2001), which also underpinned the identification and analysis of coping strategies used by children and adolescents with FA. As discussed in Chapter 1, a number of coping theories have been applied to research with chronically unwell children and adolescents, however, such theories have been met with criticism regarding their applicability to a child and adolescent population. Therefore, I decided to use the CBMC (Compas et al., 2012) a theory not yet applied in FA research, but widely used in research across a range of paediatric chronic health conditions.

The findings presented in this thesis are novel in their contribution to theory, one that was yet to be used in FA research. The findings from the systematic review and the qualitative studies demonstrated that children and adolescents with FA used coping strategies that were indicative of primary control (for example, problem solving, seeking social support) secondary control (for example, acceptance, cognitive restructuring) and disengagement coping (for example, avoidance) described by the model, demonstrating the model's applicability to coping with FA. These strategies were also congruent with those identified across other chronic health conditions applying the CBMC, such as diabetes and chronic pain (e.g. Compas et al., 2006; Graue et al., 2004; Hocking et al., 2011). The findings of this thesis therefore add to what is known and understood about coping in children and adolescents with a long-term condition, and in particular the strategies associated with the CBMC.

Compas et al. (2012) highlighted the importance of controllability in understanding the coping strategies used by children and adolescents, and I found this to be the case with children and adolescents coping with FA. FA is unique as whilst individuals can to the best of their abilities control their surroundings and the food they eat; these everyday actions still have a level of unpredictability and allergic reactions can occur despite taking care to avoid an allergen (Jones et al., 2014). How much control a child or adolescent with FA perceived to have, was found to influence the way they coped. For example, children and adolescents used disengagement coping strategies to avoid situations they felt they had no control over, such as eating outside of the home, and both children and adolescents expressed trepidation in coping with their FA in such locations. In contrast, children and adolescents had more confidence when a greater sense of control was perceived, using primary control coping strategies, such as problem solving, carrying medication or enquiring about food content.

The development and validation of the CS-FA is a further contribution to the field, and to date the scale is the first coping scale developed for children and adolescents aged 8-16 years old with FA using the CBMC. Furthermore, the subscales of the CS-FA map onto the constructs of the CBMC (see Chapter 6, table 6.24), further supporting the suitability of this model for explaining how children and adolescents

cope with FA. The scale was developed following gold standard the guidelines for scale development set out by Pesudovs et al. (2007), DeVellis (2017) and Carpenter (2018), and demonstrated good reliability with Cronbach's α values above 0.7. A test re-test analysis also demonstrated that the scale has stability over time. This demonstrates that the CS-FA is a valid and reliable measure that can be used to identify what coping strategies are being used by children and adolescents with FA. The scale could be used by HCPs to direct their advice to children and adolescents in their FA management, and could also be used to inform the effectiveness of interventions designed to help children and adolescents cope.

My research has also highlighted areas in which coping with FA does not fit with the CBMC model. One issue is how risk-taking fits within the model. Some research has indicated that passive/avoidant coping strategies such as denial and behavioural disengagement are associated with increased health risk behaviours (Schwartz et al., 2008). Within the CBMC, disengagement coping refers to efforts to distance oneself away from the stressor (Compas et al., 2001). However, if children or adolescents cope with their FA by taking risks, such as consuming an allergenic food or not carrying their AAI, they are not necessarily orienting themselves away from a stressor or ignoring their FA, but are making an active decision to engage in those behaviours. Another issue is how avoidance as a coping strategy is reflected in the CBMC. Children and adolescents demonstrated avoidance that could be adaptive and beneficial to health (avoiding allergens), and avoidance that could be maladaptive and unhelpful (avoiding social events). DunnGalvin et al. (2009) describe a continuum on which coping strategies can lie, and in this case, avoidance falls on a continuum which is reflected as both primary control and disengagement coping. A model of coping specific to FA could consider including a construct that recognises risk-taking behaviours as a coping strategy in its own right, and take into account coping strategies that serve more than one function, such as that of avoidance.

7.6. Implications for food allergy research and clinical practice

The findings of this thesis have implications for FA research and clinical practice. As highlighted in this thesis, there is a lack of research in FA that primarily focuses on coping, and the systematic review in particular highlighted an underrepresentation of research on children below the age of 11. Much of FA research has focused on QoL and psychosocial functioning, and whilst we have an understanding of how FA affects these aspects, it was not clear how children and adolescents coped with their FA. Of the few studies that have investigated coping with FA, none used an established model nor a validated measure of coping to explain the coping strategies being used by this population.

The findings of this thesis lay the foundation with which coping research in FA can be further developed. Using the CBMC, a novel contribution to FA research, provides an understanding of the types of coping strategies being used. The inclusion of children below the age of 11, means we are able to understand the experiences of younger children with FA, and how they cope. Indeed, the coping strategies of

younger children identified in this thesis did not starkly differ from their adolescent counterparts, which in itself is an important finding for FA research. It demonstrates that children are able to cope with their FA independently like adolescents and are able to cope with their FA in creative ways and make use of things such as technology to enhance the way they cope. We have a better understanding about how FA can make a child feel, and concerns around identity that are often associated with adolescence can also be a concern in childhood.

The adolescents who took part in the interviews for this thesis discussed very little risk-taking behaviour such as consuming allergenic foods. Those who did engage in risk with foods modified the risk, indicating some awareness of the risk to health. Some adolescents did not carry their medication, but this was in the minority, and rather, adolescents were mindful of the risk of not carrying an AAI. Adolescents were also found to plan ahead and used technology to cope and as a way to help make informed choices. Although the adolescents who took part in this research may have been more risk averse or did not want to talk about times when they took risks, we as researchers may over-estimate the extent to which adolescents are reckless and take risks, a perspective shared by Gallagher et al. (2012). Though fatalities and attendances to emergency departments are described to be more common in this age group, it is not necessarily due to individual taking risks with their health. Rather, it may be due to the other factors such as the preparation of food outside of the home, and knowledge others have of FA that contributes to these worrying statistics which has been identified in previous research (Nowak-Wegrzyn et al., 2001 Pumphrey & Gowland, 2007; Sicherer et al., 2001; Versluis et al., 2015).

The findings from this thesis have also highlighted that FA research should also focus on the individual diagnosed in later childhood or adolescence. The findings in Chapter 5, and previous research identified in my systematic review (Mackenzie et al., 2009) highlights that a later diagnosis can affect how an individual views their FA, and how it is managed. As there is a shorter amount of time to adapt to a FA diagnosis, the development of adaptive coping strategies may be hindered. As such, it is important to understand how this group cope, and what can be done to facilitate the use of adaptive strategies, for example, better FA education or training. Clinicians may need to spend extra time ensuring that children and adolescents who are diagnosed later, have the adequate support and access to training needed.

The development and validation of the CS-FA is not only a contribution to the field, but to FA research and clinical practice. The CS-FA can now be used in FA research with children and adolescents aged 8-16 years old as a way of identifying what coping strategies have been used, which has been lacking in current coping literature in FA. The scale has been validated across other measures, such as the FAQLQ-CF/TF and the RCADS, and associations between coping with QoL and psychological functioning have been identified. Future research further exploring QoL and psychological functioning in this population will be able to use a FA specific validated scale to explore the role of coping in adjusting to FA, and the associations between different coping strategies and these constructs.

Clinicians who regularly work with children and adolescents with FA can use the CS-FA as a way of understanding how their patient is coping. Rather than a measure of how 'well' a child or adolescent is coping, the CS-FA can open up a dialogue between the patient and clinician by identifying where there are struggles, if any, and why they might be experiencing these challenges. Though the findings in this thesis did not identify large amounts of risk-taking behaviour, research has indicated that this age group is associated with an increase in food-induced anaphylaxis, increases in visits to hospital emergency departments and the highest proportion of deaths from anaphylaxis (Bock et al., 2001; McWilliam et al., 2018; Motosue et al., 2017; Pumphrey & Gowland, 2007). Being able to understand what coping strategies are being used may help to prevent these negative outcomes and provide an opportunity to educate children and adolescents in developing and using effective coping strategies. The findings in Chapters 3, 4 and 5 showed that disclosure to others about FA can be challenging. If this is highlighted on the CS-FA, clinicians could also work with helping children and adolescents plan or practice how they could inform friends, peers and others about their FA.

The findings of the systematic review and the qualitative data indicated that there are issues with how much a child or adolescent knows about their FA and how it is managed, for example using an AAI. Although some of the children and adolescents described attending refresher AAI training sessions at their clinics, these training sessions may be too infrequent, particularly if an individual has not experienced a reaction in the past or for a long period of time, or of a poor quality. Regular training sessions across different aspects of FA management will be helpful in supporting the child or adolescent to develop and use adaptive coping strategies.

It also is important for clinicians to regularly train parents as research has shown that parents can forget how to use an AAI shortly after being trained (Umasunther et al., 2015), and parents will be the first port of call for a child or adolescent. An online training module that can be accessed from home could be developed, particularly if clinicians do not have time to regularly train parents, or there is a long period of time between routine allergy appointments. Research has shown that mothers of children with diabetes are able to cope more effectively with more knowledge of diabetes and better education (Mahfouz, Kamal, Mohammed & Refaei. 2018). As previously mentioned, if parents do not feel confident in being able to cope with their child's FA, this may translate to how they manage their child's FA and how much protection or indeed over-protection they place upon their child, and how much this affects how their child copes independently later on (Power, 2008). In fact, research (DunnGalvin et al., 2009) has found that parental coping is critical in children's risk perceptions of allergy, anxiety and coping over time.

Lastly, children and adolescents with FA should have access to appropriate psychological support. As identified in Chapter 4, such support was helpful, yet could be difficult to access (Chapter 5). Evans and Rouf (2014) state that the psychological and social impacts of allergy are not normally part of the care package provided to those with FA, yet research has shown that psychological support can be beneficial

(Scholten et al., 2013). Psychologists can help individuals to think about allergy not just as a medical issue, but more widely as a family and social issue, provide psychoeducation and psychological intervention, as well as training for other professionals to be psychologically aware of issues facing those with FA (Evans & Rouf, 2014). Therefore, it is important for clinicians to incorporate the role of psychological support as a pivotal part of the care package.

7.7. Recommendations for allergy charities and support groups

The findings from the qualitative studies in both chapters 4 and 5 have given insight into the types of strategies used by children and adolescents. Allergy charities and/or support groups should be able to share 'tips' and 'tricks' with this age group, which could include how to speak to others, such as friends or peers, about FA, or how to look for allergen information at restaurants whilst on-the-go, such as accessing menus on the phone as demonstrated in Chapter 5. The Internet was a source of information for both children and adolescents in Chapters 4 and 5, and allergy charities and support groups should develop resources and 'tips' that children and adolescents can access via the Internet. Such resources are already available for parents, for example, on the websites of Allergy UK and the Anaphylaxis Campaign, and with children and adolescents accessing the Internet more readily, such online resources should be extended to this population.

Videos and visual aids were also found to be useful in Chapter 4, and this is another avenue that allergy charities and support groups could explore to communicate ways of safely managing FA, such as how to use an EpiPen or read food labels, or examples of how to talk about FA with others. This would not only tap into the modern way of obtaining information in this age group, but would ensure that information that is trustworthy and from a reputable source can be accessed at home from the home. This would be advantageous for children and adolescents particularly if there are long periods of time between medical appointments with allergists, and if they are curious to know more about their FA.

7.8. Future directions for research

The findings of this thesis lay the groundwork for further research in coping with FA. Future directions for FA research should include further work with younger children with FA, particularly as one of the limitations to the qualitative study with children (Chapter 4), was that the majority of children in that study were aged 10 or 11 years old, and younger children were still underrepresented. Longitudinal work starting from aged 8 to aged 16 (the age range of the CS-FA) by assessing the types of coping strategies used over time, would also help to identify whether strategies used to cope with FA change as children and adolescents become older.

Validation analysis of the CS-FA with the KidCOPE and the FAIM identified a number of medium sized correlations that were not significant. As mentioned in Chapter 6, this was likely due to the analysis being underpowered, particularly as for these two measures, the sample had to be split further according

to age. Future research could look to increasing the sample size to meet the minimum sample required to identify significant results.

Although the discriminative validity analysis of the CS-FA (Chapter 6) did not identity statistically significant differences in the coping strategies used amongst different types of FA, this thesis examined FA more broadly, rather than focusing on specific types of FA. As a result, there may have been challenges associated with certain types of FA that were not uncovered in this research. In the qualitative studies, there were indications that certain types of FA could be more difficult to manage than others. For example, Francis (Chapter 4), felt that a dairy allergy would be more difficult to manage in comparison to his peanut allergy, as it would restrict what he would be able to eat, whilst Rachel (Chapter 5) felt that a dairy allergy was a "bit more unknown".

An American and British study (Howe et al., 2014; Knibb, Barnes & Stalker, 2006) found certain types of FA, such as dairy and eggs, negatively impacted the QoL of parents of children with FA .This may be due to the abundance of dairy and eggs in the diets of these two countries which makes it difficult to avoid that ingredient. With the age group studied in this thesis, it is likely that the challenges of diet are less felt by children and adolescents as they will not be responsible for buying or preparing food. However, as children and adolescents become more autonomous and start to buy food or snacks without their parents, such challenges may be identified which could affect how one copes, and this warrants further investigation.

Research should also examine whether uncommon types of FA, such as that of rapeseed oil (Helen, Chapter 5) could affect the types of coping strategies used. Not only did Helen have difficulty in coping with her FA safely as the labelling for rapeseed oil could be inconsistent, leading to uses of avoidant coping strategies as she was not certain she could keep herself safe, access to social support was also limited as it was difficult to find support groups for her type of FA. It may be that differences in coping strategies are more obvious when comparing common FA with uncommon FA, particularly if the latter presents difficulties such as those experienced by Helen.

It is also possible that as nearly half of those who completed the CS-FA, and nearly all the children and adolescents interviewed had multiple FA, that children and adolescents have learned to adapt and to cope with their FA using the same coping strategies regardless of the type of food that requires avoiding. In order to draw any conclusions, further understanding is needed of the demand's certain types of FA place upon the individual, to ascertain what effect, if any, different types of FA have on coping strategies. Mixed-method studies with a broader range of FA, including uncommon types of FA is required.

As discussed earlier, repeated education is important (Taddeo et al., 2008) and can affect the types of coping strategies used (Asnani et al., 2017; Moradkhani et al., 2011). However, only one child in Chapter 4, Callum, could remember being taught how to use an AAI by their doctor. For adolescents in Chapter

5, FA education by HCP's was not mentioned. Future research should look to examine the association between FA education (such as allergen avoidance, label reading, and use of AAIs) and the effect this has on how children and adolescents with FA cope. A focus should be placed on the quality and frequency of educational sessions, particularly as research has shown that both can affect how well information is remembered (Blyth & Sundrum, 2002; Gold & Sainsbury, 2000; Umasunthar et al., 2015). As the findings in the qualitative chapters have shown the role the Internet can have on FA management, research could be conducted on the feasibility and effectiveness of online FA educational or training sessions for both the patient and their parents. The accessibility of such sessions could bridge the gap between routine appointments and ensure that information given at appointments is retained beyond the clinic room.

Research by Coulson and Knibb (2007) and Jones et al. (2018) has highlighted the benefits of peer support groups for patients with FA. However, in my interviews I talked to a minority of children and adolescents accessing peer support groups. As the benefits of peer support have been documented for adolescents, young adults and adults with regards to developing coping strategies and adherence to self-care behaviours, there is scope for research to investigate the accessibility and uptake of peer support groups, and assess the usefulness of such groups particularly for children with FA, a group that was not included in the research conducted by Coulson and Knibb (2007) and Jones et al. (2018).

Future research could also explore the role that parents play in the coping strategies used by their child. Although this was only briefly touched upon in Chapter 4, the perception of danger of eating out in a restaurant modelled by a parent influenced one child to also feel unsafe eating in restaurants. Furthermore, the use of downward social comparisons, FA hierarchies and positive reinterpretation and the language with which these coping strategies were described may also suggest that parents or adults may model this way of thinking to their child. The role of parental influence in coping has been explored by Power (2008), who posits that parental protection is 'not always a good thing' (pg. 278), that children must learn to adapt to difficult situations, and some children may have limited experience with certain kinds of stressors due to 'overprotective' parenting. This would require a detailed examination into understanding how children and adolescents come to learn the coping strategies they use, and what influences their parents have on the ways in which children and adolescents cope.

The CS-FA itself needs to be subjected to further empirical work as the data presented in this thesis only represents preliminary reliability and validity data for a UK population. As highlighted in Chapter 6, a larger sample size is required to fully establish the stability of the CS-FA over time. Confirmatory factor analysis is needed to confirm the existence of the sub-scales. The reliability and validity of the scale in samples of children and adolescents from different countries should be explored. Other types of validity can also be measured, such as the sensitivity of the scale to changes in the use of coping strategies after an intervention. Finally, the scale may prove to be too time-consuming for completion in clinical settings and a short scale could be developed and assessed for reliability and validity in clinical settings.

Finally, the CBMC had not previously been used before in the context of FA. Therefore, it is difficult to establish whether the CBMC is truly the most appropriate model of coping to be applied to this population as there is no existing research using the CBMC in the context of FA that my findings could be compared with. Whilst it was possible to compare findings with other chronic illnesses that have used the CBMC, such as T1D or chronic pain, FA is a unique condition where allergic reactions and possible fatalities can occur at a very fast rate, in contrast to chronic conditions such as TID or chronic pain. One particular issue lies with the issue of avoidance as a coping strategy, which Compas et al. (2012) categorise as a form of disengagement coping. DunnGalvin et al. (2009) describe a continuum on which coping strategies can lie, and indeed coping strategies can have more than one function as evidenced by how 'avoidance' was used by children and adolescents with FA in this study. Throughout this thesis, avoidance as a coping strategy was found to be both adaptive in terms of avoiding allergens to prevent an allergic reaction (which was coded as primary control coping), but also unhelpful if avoidance involves avoiding discussing or disclosing FA with others or social situations deemed as high risk (which was coded as disengagement coping**).** This could also explain why during the development of the CS-FA, that avoidance coping in its different forms appeared as both a primary control coping strategy (avoiding allergens) and a disengagement coping strategy (avoiding social situations that are high risk, avoiding disclosing FA to others), leading to the identification of four factors during scale development, rather than the three factors associated with the CBMC. Therefore, it is possible that the CBMC as a model to explain coping behaviours in children and adolescents with FA, may need further work or adaptation to take into account the 'continuums' that can appear within coping strategies.

However, as argued in Chapter 1, the CBMC is a coping model based upon a paediatric population and more sophisticated in its ability to categorise coping strategies in contrast to the traditional two-factor problem-focused and approach/avoidance coping models. I would argue that the CBMC continues to be the most appropriate model of coping available to a paediatric population in comparison to other models of coping, which have been developed based on adult populations.

7.9. Strengths and limitations

A major strength of this thesis is that it employed a mixed-methodological approach. The systematic review was the first, to my knowledge, to review how children and adolescents cope with FA. As highlighted in the systematic review, there was a need for research that firstly focused on coping, and secondly included children under the age of 11 years old, who were an underrepresented group. From the individual interviews conducted with both children and adolescents, I was able to gain rich data that described their experiences of living with FA, and how they coped with the condition. Determining the point at which data saturation had been achieved required a combination of a careful consideration of the narratives of the children and adolescents I interviewed, the research question of this thesis, and my own position and experience of previously working within a clinical facing role with children and adolescents with chronic health conditions. The detailed analysis of the interview data was subject to

regular discussions and meetings with the supervisory team which helped to ensure the validity of the findings.

An additional strength lies within the quantitative element of this thesis. There was rigour in the development and validation of the CS-FA by following the guidelines of scale development proposed by Pesudovs et al. (2007), DeVellis (2017) and Carpenter (2018). Though the goal of achieving 300 participants to complete the CS-FA was not met, I was able to run the necessary analyses on the CS-FA required to firstly reduce the scale and identify a factor structure, and to assess for reliability and validity. Additionally, there was a good mix of age and gender for both children and adolescents completing the scales.

The use of the CBMC to underpin the identification and analysis of coping strategies in children and adolescents is a further strength to this thesis. This model had not been previously applied to FA research and is a well-established model of coping in research with children and adolescents with chronic health conditions. This thesis provides findings that future research can build upon, to identify and understand how children and adolescents with FA cope, to explore the relationship that coping can have on other domains such as QoL and psychosocial functioning, and to potentially inform the development of interventions to support development of adaptive coping for this population.

There were, however, limitations to the work presented in this thesis. Within the qualitative studies, more boys aged 8-11 took part and more girls aged 12-16 took part. Therefore, it is possible that this thesis is missing in-depth detail and experiences of younger girls and adolescent boys. Whilst the qualitative study with children (Chapter 4) sought to remedy the underrepresentation of children in FA research, the majority of children that participated were aged 10 or 11 years old. Whilst I was able to interview children aged 8 and 9 years old, a greater understanding of the experiences and coping strategies of younger children in this group may have been possible if more children this age participated in this research.

Of the children and adolescents I interviewed, only one adolescent had a recent diagnosis of FA, and at a later age in comparison to the rest of the participants. The narrative differed in the way she was managing and coming to terms with her FA. Whilst I did not set out to investigate whether duration of diagnosis affected how individuals cope with FA, the narrative provided by this participant highlights an important concept that needs to be considered in coping research. However, with only one participant in this position, it cannot be concluded that many of those diagnosed in later childhood or adolescence feel the same way. A better understanding of how it is for those diagnosed later in terms of adjustment to a diagnosis of FA and how they cope with the condition would have been possible if more participants in that position took part in the study. It is possible that there will be patients who were diagnosed later in childhood or adolescence, who take the diagnosis and management of FA in their stride and are able

to use adaptive coping strategies. However, without being able to interview more children and adolescents in that position, I was unable to further investigate this.

There are also limitations concerning the sample with regards to the development and validation of the CS-FA. As discussed in both Chapters 4 and 5, the majority of children and adolescents interviewed were White British, with multiple allergies, and largely appeared to be coping well. Therefore, the development of the CS-FA is predominantly based upon this population, and unfortunately does not include items developed on a population where children and adolescents were not coping well, had a single FA diagnosis, and from a range of different ethnicities.

As identified in Chapter 6, the sample was skewed towards 'White-British' children and adolescents, with a diagnosis of peanut allergy or other types of nut allergy. Therefore, this means that the questionnaire was largely tested and validated by this population, which could have implications regarding its applicability in wider use. Secondly, the validation analysis of the CS-FA, particular with the KidCOPE and FAIM was underpowered to detect significant results as the sample had to be split further according to age group. The sample for the test re-test phase of the CS-FA is also skewed towards White-British' children and adolescents, with a diagnosis of peanut allergy or other types of nut allergy, which again has implications regarding its applicability as a measure in a wider population.

Whilst it was required that participants had a clinical diagnosis of FA, a further limitation is the reliance on a self-report of a FA diagnosis, rather than confirmation from an allergic clinic of a clinical diagnosis of FA. Though the parents of the children and adolescents I interviewed in Chapters 4 and 5 were able to confirm that their child had a clinical diagnosis of FA through their narrative of who and where their diagnosis was obtained, as previously mentioned, we cannot rule out that there may be children and adolescents who completed the CS-FA and the validation scales who did not have a clinical diagnosis of FA. This may have potentially affected the data obtained, particularly if differences coping strategies exist between those with and without a clinical diagnosis of FA.As previously mentioned in Chapter 6, the number of participants taking part in the test re-test of the CS-FA and those completing the FAQLQ-CF/TF was very low. It is possible that this was due to the burden of the time it would take to complete the questionnaires which may have been off-putting for some prospective participants. Consequently, the test re-test and the exploration of coping strategies associated with QoL were underpowered. This has probably resulted in missing the identification of relationships that exist between the CS-FA and QoL.

7.10. Conclusion

This empirical research in this thesis has generated new knowledge about how we understand how children and adolescents with FA cope. Firstly, this thesis has applied the CBMC, a model of coping that has been applied to research with children and adolescents with chronic health conditions, to explain how children with and adolescents with FA cope, something which had not yet been done. The

identification of primary control, secondary control and disengagement coping strategies using this model, demonstrates the applicability of the CBMC to explain coping in FA.

Secondly, the research from the qualitative chapters of this thesis, has provided in-depth knowledge specifically focused on coping, which was lacking in current FA literature, an issue highlighted in the systematic review in Chapter 3. Additionally, this thesis contributes to the understanding of how children, particularly under the age of 11, cope with their FA as this age group were underrepresented in the systematic review. In particular, the findings of the interviews with children have shown that they have an awareness and understanding of the risks associated with FA, are able to independently cope with their condition, and also teach themselves strategies to cope more effectively. The findings from the interviews conducted with adolescents have highlighted that adolescents, who are typically associated with risk-taking behaviours, demonstrated planful behaviours when socialising outside of the home, and would minimise the risks to their health. Technology also played a role in both age groups in how they coped, a finding that to my knowledge, had not been identified previously in FA research.

Lastly, the development and validation of the CS-FA is a novel contribution to the field, and further demonstrates the applicability of the CMBC with FA as the subscales mapped onto the constructs of the model. This is the first coping scale for FA that has been developed using in-depth primary data with children and adolescents and validated with the same population. This scale provides opportunity for further research into coping within this population, which can further add to the FA literature.

7.11. Reflexive account of the research experience and analysis

As defined in Chapter 2, reflexivity refers to the influence of the effect of the researcher, and their prior experiences and assumptions, has on the data (Mays & Pope, 2002). For the purpose of this thesis, I will highlight my own research and professional background and my reflexive account is given below:

I am a young female of mixed-race heritage and have just entered my thirties. My academic background is in psychology, and prior to starting this Ph.D., I had spent over five years working in the NHS as an assistant clinical psychologist, with two of those years within a paediatric psychology service, working with children with a range of chronic health conditions though this did not include children and adolescents with FA. Through my previous university degrees and my career, it is obvious that I have keen interest in psychology and the experiences of other people and how it shapes their reactions to the world around them.

During the qualitative element of my thesis, I was aware that my position as a 30-year-old woman, a former healthcare professional and now as a researcher would impact the research, what children and adolescents would disclose to me, and my interpretations of the interviews I conducted with them. Primarily, I had worked with adolescents rather than younger children, and I felt particularly aware of myself and how I communicated with younger participants during interviews with them. I often had questions during the interview and analysis process; was I using age-appropriate language? Did they

fully comprehend the questions I was asking? Having no diagnosis of FA myself, no close family or friends with the condition, and no prior experience of working with children and adolescents with FA during my time spent working as an assistant psychologist in paediatrics, I was keenly aware of the potential of having an unconscious bias towards children and adolescents with chronic health conditions generally based on my previous experiences at work. How much of my prior experience could I use without clouding my judgment during the analysis? I found it helpful to discuss these thoughts with my supervisory team during the interview process and analysis, to be able to separate what was emerging from the data and what was coming from my own experience in order to ensure my analysis was not biased.

I had to quickly learn to separate my present self as the researcher from my former self as the healthcare professional working within a therapeutic context as I was used to being in a 'therapist' role rather than one as a 'researcher'. I reflected back to my own childhood and the frustrations of feeling "interrogated" or repeatedly asked to clarify things, and I wanted to avoid generating those feelings in my participants as they were providing me with their data for my benefit, for my research. From my experience of working paediatric patients, I anticipated that the boys would not be forthcoming in wanting to open up to me. However, I was taken back by their openness with which they shared their experiences with me and found that the level of openness between both boys and girls were very similar. On reflection, I wondered if it was the way in which data was collected, and my experience of working with chronically unwell children of the age group of my research that may have helped with engaging with them during the interview process.

I wondered how engagement would be affected, particularly when interviews were conducted over Skype, rather than in person where it would be easier to read body language. However, I found that despite the "barriers" caused by interviewing over Skype, many children enjoyed being able to use technology and were still able to interact with me in the same way as they would have done if we interviewed in person, for example, showing me their medication via video camera.

I also reflected on the participants who may have been struggling to cope with their FA but had not chosen to participate in my research. I first looked at this as 'lost data' and wondered whether their experiences may have changed the way I analysed my results. I was concerned of being biased within my analysis as I was mindful that the children and adolescents who had chosen to participate were generally coping well and describing largely positive experiences that they were very willing to share with me. I felt pressure to do their stories and experiences justice, to be able to separate their stories from the previous research when interpreting their data. I have had to come to accept that qualitative data can be incredibly rich and it can be difficult to encompass everything that has been discussed in one chapter, that what I have found through my discussion with children and adolescents is not wrong in the context of existing research, but is a reflection of the thoughts and experiences of those children

and adolescents who chose to take part and find myself fortunate to be able to be in a position to share their experiences through this research.

Unlike the flexibility of qualitative analysis, with quantitative data, I was bound by what the numbers were telling me and what the results meant. At times, I became disheartened when items of the prototype scale did not reach the final CS-FA as the analysis deemed it to not be 'good enough'. I was concerned that this would isolate a group of children and adolescents who would perhaps use that particular coping strategy. However, through continuous supervision and discussion of the items being retained in the scale, I felt more comfortable with the items retained in the final CS-FA, and hoped that this scale would reflect, to the best of its ability, the coping strategies used by this population.

During the course of the research process, I kept a reflective diary which was helpful as I started to piece together this puzzle that is my thesis. Being able to read back on my thoughts, how I came to a particular conclusion, and the process of developing the scale helped with my narrative. One thing that I found myself repeatedly writing throughout my reflective diary was "do I need more data?". This was likely due to my own anxieties of whether I was making the voices of these children and adolescents heard. 'Data' seems like such a crude word on reflection, and going forward in my career, I want to humanise this phrase more. This research experience, from conducting the studies to writing the thesis, has not only challenged me on what I thought I would understand about FA, but also how I see myself as a researcher. I have learnt more than I thought was possible, but most importantly, this journey has allowed me to voice the narratives of these individuals, and to convey these stories whether through words or in numbers.

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Appendices

Appendix 1: **10 Steps to scale development (Carpenter, 2018)**

1. Research the intended meaning and breadth of the theoretical concept	a. Select appropriate conceptual labels b. Select conceptual definitions c. Identify potential dimensions and items d. Conduct qualitative research to generate dimensions and items i. Use feedback to refine scale i. Expert feedback, pre-tests, cognitive interviews, or pilot tests can be employed to evaluate item wording, item validity, questionnaire design, and model structure
2. Determine sampling procedure (5:1)	
3. Examine data quality	
4. Verify the factorability of the data	a. Bartlett's Test of Sphericity (≤.05) b. Kaiser-Meyer-Olkin test of sampling adequacy (≥.60) c. Inspect correlation matrix (≥.30)
5. Conduct Common Factor Analysis	
6. Select factor extraction method	a. Principal Factors Analysis b. Maximum Likelihood
7. Determine number of factors	a. Theoretical convergence and parsimony b. Scree test c. Parallel Analysis (PA) d. Minimum Average Partials (MAP)
8. Rotate factors	a. Oblique rotation (Direct Oblimin, Promax)
9. Evaluate items based on a priori criteria	a. Theoretical convergence b. Parsimony c. Weak loadings (≥.32) d. Cross loadings e. Inter-item correlations f. At least three-item factors g. Communalities of items (≥.40)
10. Present results	a. Scale and subscale naming logic, conceptual definitions, sample size logic, methods for determining factor numbers, Bartlett's test of sphericity, Kaiser-Meyer-Olkin test of sampling adequacy results, factor extraction method, rotational method, strategies for deciding on items, eigenvalues for all factors, pattern matrix, computer program package, communalities for each variable, descriptive statistics, subscale reliabilities, and percentage of variance accounted for by each factor.

Adapted from Carpenter, S (2018) Ten Steps in Scale Development and Reporting: A Guide for Researchers, Communication Methods and Measures, 12:1, 25-44,

Appendix 2: **Data extraction form**

Review title or ID	
Study ID *(surname of first author and year first full report of study was published e.g. Smith 2001)*	
Report ID	
Report ID of other reports of this study	
Notes	

GENERAL INFORMATION

Date form completed *(dd/mm/yyyy)*	
Name/ID of person extracting data	
Reference citation	
Study author contact details	
Publication type *(e.g. full report, abstract, letter)*	

Study Characteristics	Eligibility criteria *(Insert inclusion criteria for each characteristic as defined in the Protocol)*	Eligibility criteria met? Yes No Unclear	Location in text or source *(pg & ¶/fig/table/other)*
Sample		☐ ☐ ☐	
Phenomenon of interest		☐ ☐ ☐	
Design		☐ ☐ ☐	
Evaluation		☐ ☐ ☐	
Research type	Qualitative	☐ ☐ ☐	
	Quantitative		
	Mixed-method		

INCLUDE ☐	EXCLUDE ☐
Reason for exclusion	
Notes:	

DO NOT PROCEED IF STUDY EXCLUDED FROM REVIEW

Characteristics of included studies

METHODS

	Descriptions as stated in report/paper	**Location in text or source** *(pg & ¶/fig/table/other)*
Aim of study *(e.g. efficacy, equivalence, pragmatic)*		
Design*(e.g. parallel, crossover, non-RCT)*		
Notes:		

Participants

	Description	Location in text or source *(pg & ¶/fig/table/other)*
Population description *(from which study participants are drawn)*		
Setting *(including location and social context)*		
Diagnosis of FA/FHS/FI		
Method of recruitment of participants *(e.g. phone, mail, clinic patients)*		
Age range		
Sex		
Race/Ethnicity		

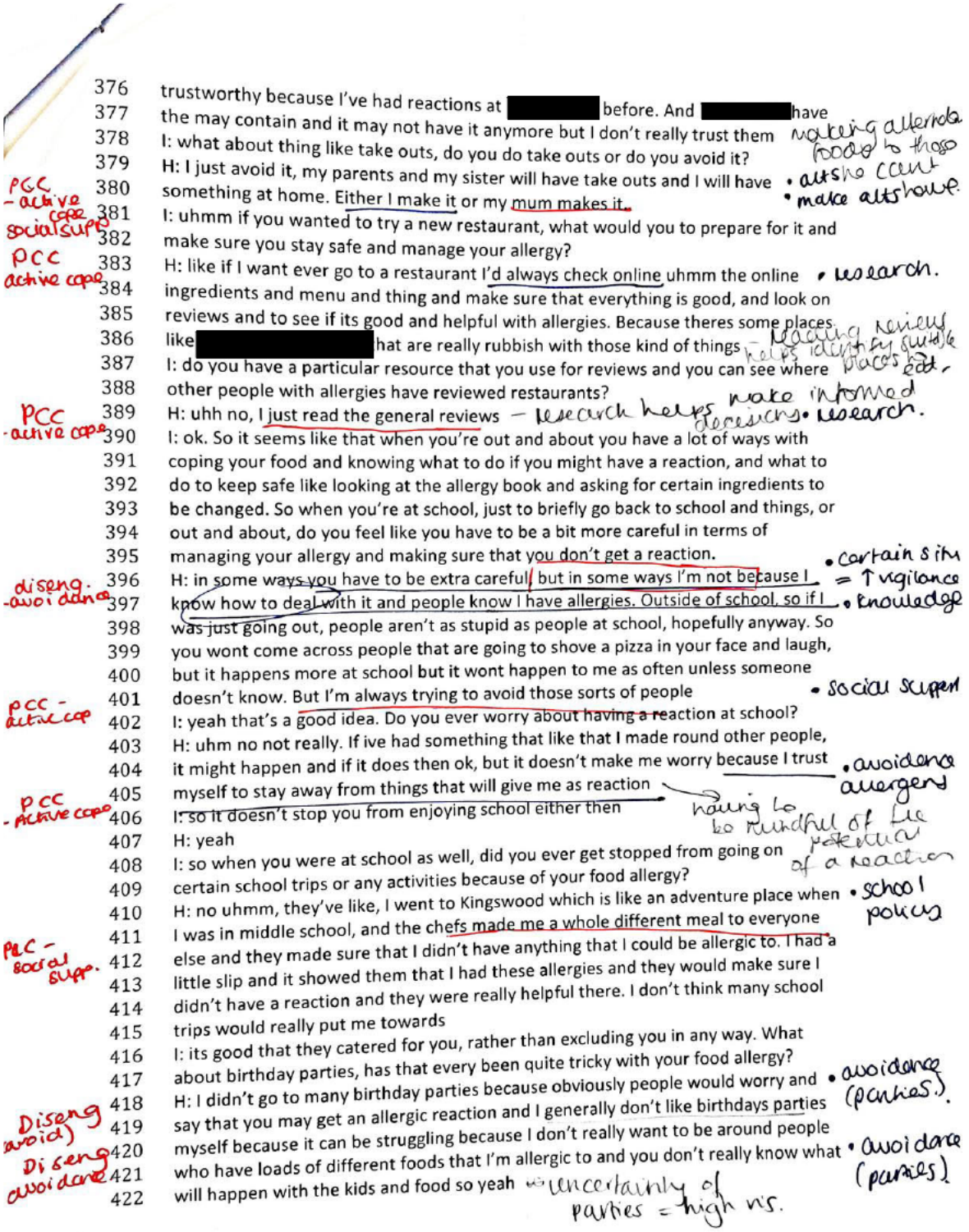
Results

Analysis method used*)*		
If appropriate – report quantitative findings		
If appropriate – report qualitative findings		
Does it answer review aims?		

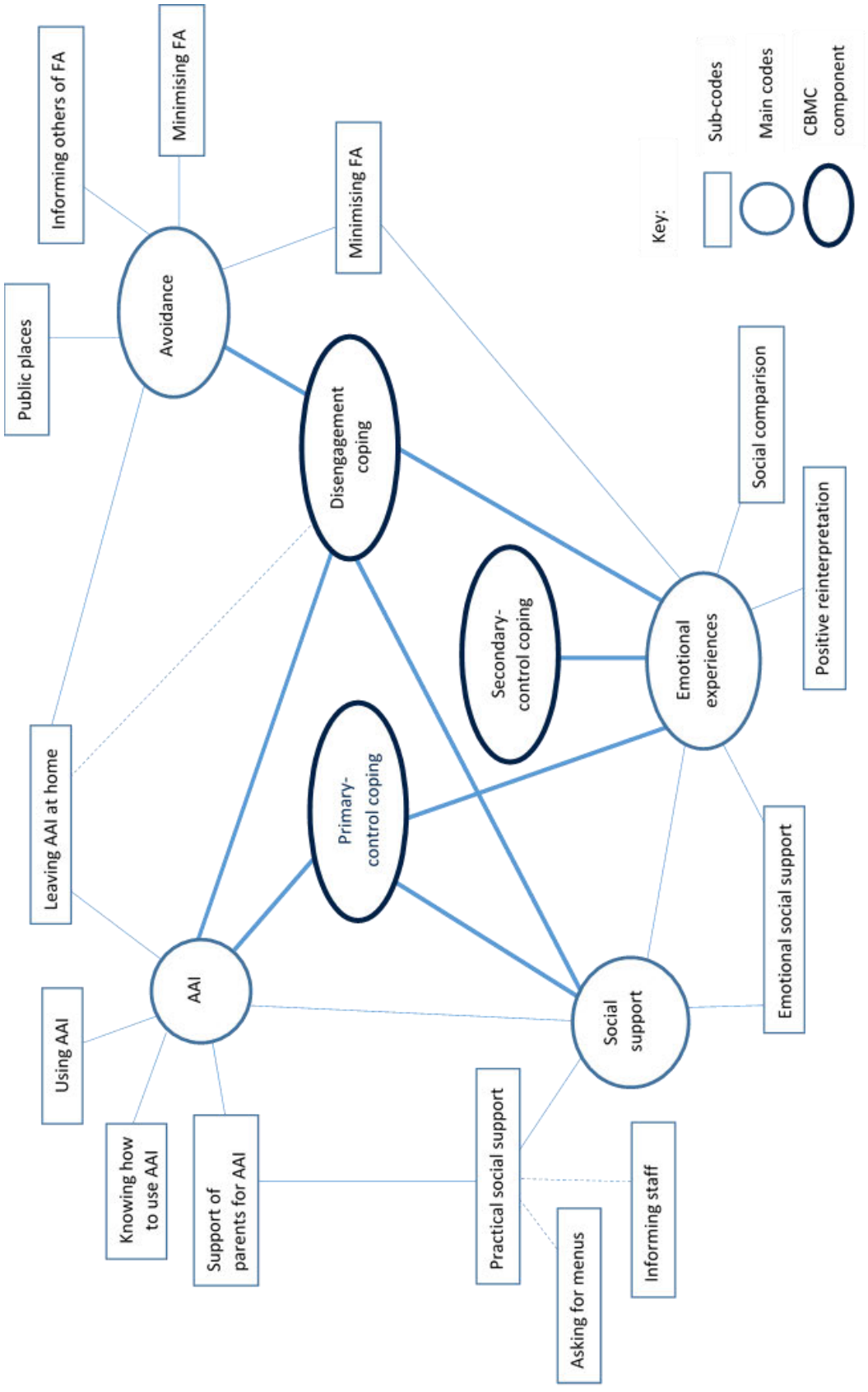
Appendix 3: **MMAT tool (Pluye et al. 2011)**

Appendix 4: **Example coding**

Red text – deductive coding
Black text – inductive coding



Appendix 5: **Example thematic map**



Appendix 6: **Excluded studies**

		Reasons for exclusion			
Author, Year	**Title**	**Participants not children or adolescents with FA**	**Participants outside of the age range**	**Outcomes do not describe coping e.g. depression, anxiety, QoL**	**Review/paper/book chapter/letter to the editor/abstract only with no primary data**
Abdurrahman et al. (2013)	"Experiencing a First Allergic Reaction to Food: A Qualitative Study of Parent And Caregiver Perspectives."	X			
Aika et al (2017)	"Food allergy response capabilities of mothers and related factors"	X			
Aktas et al (2018)	"Development and Implementation of an Allergic Reaction Reporting Tool for School Health Personnel: A Pilot Study of Three Chicago Schools"	X			
Allen et al. (2009).	"Food allergy: Is strict avoidance the only answer?"				X
Allen et al. (2007).	"EpiPen use in children with food allergies."				X
Allen et al. (2009).	"Management of cow's milk protein allergy in infants and young children: An expert panel perspective."			X	
Alonso-Lebrero et al. (2014).	"Everyday Life Impact On Food Allergy Spanish Children. Caregivers Perception."	X			
Annunziato, et al. (2013).	"An assessment of the mental health care needs and utilization by families of children with a food allergy."	X			
Annunziato, et al. (2015).	Allocation of food allergy respons bilities and its correlates for children and adolescents.			X	
Arkwright (2009).	"Automatic epinephrine device use in children with food allergies."				X
Atkins (2011)	"Are we still missing the point(s) when managing children with food-related anaphylaxis?"			X	
Began et al (2017)	"Parents' and caregivers' experiences and behaviours when eating out with children with a food hypersensitivity"	X			
Bendelius (2002).	"Food allergies and label reading: a healthy relationship				X
Brantlee Broome-Stone (2012).	"The psychosocial impact of life-threatening childhood food allergies."				X
Budnitz et al (2014)	"Adherence to label and device recommendation for over-the-counter pediatric liquid medications"			X	
Burton et al. (2010).	"Understanding the experiences of allergy testing: A qualitative study of people with perceived serious allergic disorders."	X			
Cader (2017)	"Case study: An approach to managing food allergies in a child"			X	
Caslbeek et al (2006)	"Coping in adolescents and young adults with chronic digestive disorders: Impact on school and leisure activities."		X		

		Reasons for exclusion			
Author, Year	**Title**	**Participants not children or adolescents with FA**	**Participants outside of the age range**	**Outcomes do not describe coping e.g. depression, anxiety, QoL**	**Review/paper/book chapter/letter to the editor/abstract only with no primary data**
Cole et al. (2017)	The Cellie coping kit for children with food allergy: a pilot study			X	
Coulson & Kn bb (2007).	"Coping with food allergy: Exploring the role of the online support group."	X			
Covaciu et al. (2013).	"Childhood allergies affect health-related quality of life."			X	
Cummings et al. (2010).	"Management of nut allergy influences quality of life and anxiety in children and their mothers."			X	
Cummings et al. (2010).	"The psychosocial impact of food allergy and food hypersensitivity in children, adolescents and their families: A review."				X
Dinakar (2012).	"Anaphylaxis in children: Current understanding and key issues in diagnosis and treatment."				X
Dunn-Galvin, et al. (2006).	“Incorporating a gender dimension in food allergy”				X
Dunn-Galvin & Hourihane (2008).	“A new model for anxiety-avoidance behaviour in food allergy: Cognitive-emotional sensitisation in children.”			X	
Dunn-Galvin & Hourihane (2009).	“Developmental trajectories in food allergy: a review.”				X
Dunn-Galvin & Hourihane (2009).	“Self-Assessment of Reaction Thresholds in Food Allergy: A New Theory of Risk Taking which Changes Over Time”			X	
DunnGalvin & Hourihane. (2010).	"A Chronic Disease Impacts Directly on Child's Normal Trajectory of Psychological Development in Both a Generic and Disease-Specific Manner: Similarities and Differences in Food Allergy and Diabetes."				X
DunnGalvin, & Hourihane (2011).	"Assessment and Management of Specific Emotional and Behavioural Problems in Paediatric Food Allergy.			X	
DunnGalvin & Hourihane (2011).	Health-related quality of life in food allergy. Impact, correlates, and predictors				X
DunnGalvin, et al. (2015)	“The effects of food allergy on quality of life”			X	
DunnGalvin et al. (2018)	“Preliminary Development of the Food Allergy Coping and Emotions Questionnaires for Children, Adolescents, and Young People: Qualitative Analysis of Data on IgE-Mediated Food Allergy from Five Countries”				X
Ersig et al (2018)	“Student and Parent Perspectives on Severe Food Allergies at College”		X		
Greenhawt et al. (2009).	"Food allergy and food allergy attitudes among college students."		X		
Greenhawt (2014).	"Food Allergy Quality of Life."			X	

		Reasons for exclusion			
Author, Year	**Title**	**Participants not children or adolescents with FA**	**Participants outside of the age range**	**Outcomes do not describe coping e.g. depression, anxiety, QoL**	**Review/paper/book chapter/letter to the editor/abstract only with no primary data**
Greenhawt et al (2018)	“Current trends in food allergy – induced anaphylaxis management at school”				X
Gupta et al. (2009).	"Food allergy knowledge, attitudes, and beliefs in the United States."	X			
Gupta et al. (2010).	Food allergy knowledge, attitudes, and beliefs of primary care physicians."	X			
Gupta et al. (2010).	Food allergy knowledge, attitudes, and beliefs of parents with food-allergic children in the United States."	X			
Gupta et al. (2013).	Factors associated with reported food allergy tolerance among US children."			X	
Gupta (2014).	"Anaphylaxis in the Young Adult Population."			X	
Gupta et al (2014).	Asthma and food allergy management in Chicago Public Schools			X	
Gupta et al (2014)	“Food allergy diagnosis and management practices among paediatricians”	X			
Hu & Kemp (2005).	"Managing childhood food allergies and anaphylaxis."			X	
Hu et al. (2005).	"Risk, rationality, and regret: responding to the uncertainty of childhood food anaphylaxis."			X	
Jones et al (2014)	Explaining adherence to self-care behaviours amongst adolescents with food allergy: A comparison of the health belief model and the common sense self-regulation model.			X	
Johnson & Woodgate (2017)	Qualitative Research in Teen Experiences Living with Food-Induced Anaphylaxis: A Meta-Aggregation				X
Kelsay (2003).	"Psychological aspects of food allergy."			X	
Kemp & Hu (2008)	"Food allergy and anaphylaxis - dealing with uncertainty."				X
King et al. (2009).	"Impact of peanut allergy on quality of life, stress and anxiety in the family."			X	
Knibb & Horton (2008).	"Can illness perceptions and coping predict psychological distress amongst allergy sufferers?"		X		
Knibb & Hourihane (2013).	"The psychosocial impact of an activity holiday for young children with severe food allergy: a longitudinal study."			X	
Knibb (2016)	“The contr bution of psychology to our understanding of the impact of food allergy on people’s lives”				X
LeBovidge et al. (2009).	"Assessment of psychological distress among children and adolescents with food allergy."			X	
Leftwich et al (2011)	“The challenges for nut-allergic consumers of eating out”	X			
Lee et al (2015)	“Adherence to extensively heated egg and cow's milk after successful oral food challenge”			X	

		Reasons for exclusion			
Author, Year	**Title**	**Participants not children or adolescents with FA**	**Participants outside of the age range**	**Outcomes do not describe coping e.g. depression, anxiety, QoL**	**Review/paper/book chapter/letter to the editor/abstract only with no primary data**
Lieberman al. (2010).	"Bullying among pediatric patients with food allergy."			X	
Lieberman & Sicherer (2011).	"Quality of life in food allergy."				X
MacKenzie & Dean (2010).	"Quality of life in children and teenagers with food hypersensitivity."			X	
Mandell et al. (2005).	"Anaphylaxis: How do you live with it?"	X			
Marklund et al. (2004).	"Health-related quality of life among adolescents with allergy-like conditions - with emphasis on food hypersensitivity."			X	
Marrs & Lack (2013).	"Why do few food-allergic adolescents treat anaphylaxis with adrenaline? - Reviewing a pressing issue."			X	
Morritt & Aszkenasy (2000).	"The anaphylaxis problem in children: Community management in a UK national health service district."			X	
Motosue et al (2017)	“Predictors of epinephrine dispensing and allergy follow-up after emergency department visit for anaphylaxis”			X	
Múgica-García et al (2015)	“Self-management of anaphylaxis is not optimal”	X			
Mullins (2003).	"Anaphylaxis: risk factors for recurrence."	X			
Muñoz (2018)	“‘Everybody has to think – do I have any peanuts and nuts in my lunch?’ School nurses, collective adherence, and children's food allergies”	X			
Muñoz -Furlong, (2003).	"Daily coping strategies for patients and their families."			X	
Muñoz -Furlong, (2004).	"Patient's perspective and public policy regarding anaphylaxis."			X	
Muñoz-Furlong & Weiss (2009).	"Characteristics of food-allergic patients placing them at risk for a fatal anaphylactic episode."				X
Ng et al (2011)	“Parental perceptions and dietary adherence in children with seafood allergy”	X			
Oriel et al (2018)	“How to manage food allergy in nursery or school”				X
Polloni et al. (2013).	"Nutritional behavior and attitudes in food allergic children and their mothers."	X			
Polloni et al (2016)	“Coping strategies, alexithymia and anxiety in young patients with food allergy.”		X		
Putman (2002).	"Food allergies-keeping kids safe."				X
Ravid et al. (2012).	Mental Health and Quality-of-Life Concerns Related to the Burden of Food Allergy."			X	

		Reasons for exclusion			
Author, Year	**Title**	**Participants not children or adolescents with FA**	**Participants outside of the age range**	**Outcomes do not describe coping e.g. depression, anxiety, QoL**	**Review/paper/book chapter/letter to the editor/abstract only with no primary data**
Rhim & McMorris (2001).	"School readiness for children with food allergies."	X			
Reuter et al (2018)	"Increased Use of Adrenaline in the Management of Childhood Anaphylaxis Over the Last Decade"			X	
Saleh-Langenberg, et al. (2015).	"Predictors of health-related quality of life of European food-allergic patients."			X	
Sampson, et al. (2006)	"Risk-taking and coping strategies of adolescents and young adults with food allergy"		X		
Schorer et al (2017)	"What is new in managing patients with food allergy? Almost everything"				X
Shah & Stalets (2014).	"Anaphylaxis."				X
Shaker et al (2017)	"An update on the impact of food allergy on anxiety and quality of life"				X
Shaker et al (2018)	"A survey of caregiver perspectives on emergency epinephrine autoinjector sharing"	X			
Shanahanet al. (2014).	"Are children and adolescents with food allergies at increased risk for psychopathology?"			X	
Sicherer et al. (2001).	"The impact of childhood food allergy on quality of life."			X	
Sicherer et al (2018)	"Food allergy: A review and update on epidemiology, pathogensis, diagnosis, prevention and management"				X
Simons & Simons (2010).	"Epinephrine and its use in anaphylaxis: current issues."				X
Stensgaard et al (2016)	"Quality of life in childhood, adolescence and adult food allergy: Patient and parents perspectives"			X	
Stensgaard et al (2016)	"Green, yellow and red risk perception in everyday life – a communication tool".		X		
Stjerna et al (2017)	"Risk as a relational phenomenon: a cross-cultural analysis of parents' understandings of child food allergy and risk management"	X			
Strinnholm et al (2017)	"Health Related Quality of Life among schoolchildren aged 12-13 years in relation to food hypersensitivity phenotypes: A population-based study"			X	
Teufel et al. (2007).	"Psychological burden of food allergy."				X
van der Velde et al. (2011).	"Adolescent–parent disagreement on health-related quality of life of food-allergic adolescents: who makes the difference?"			X	
van der Velde et al. (2012).	"Food allergy–related quality of life after double-blind, placebo-controlled food challenges in adults, adolescents, and children."			X	

		Reasons for exclusion			
Author, Year	**Title**	**Participants not children or adolescents with FA**	**Participants outside of the age range**	**Outcomes do not describe coping e.g. depression, anxiety, QoL**	**Review/paper/book chapter/letter to the editor/abstract only with no primary data**
Venter et al. (2015).	"Health-Related Quality of Life in children with perceived and diagnosed food hypersensitivity."			X	
Wa kner et al. (2015)	"Quality of Life in Food Allergy Patients and Their Families."			X	
Warren et al. (2015).	"Differences in empowerment and quality of life among parents of children with food allergy."			X	
Worth et al. (2013).	"Living with severe allergy: an Anaphylaxis Campaign national survey of young people."			X	

Appendix 7: **Child information sheet (interviews)**

Sandwell and West Birmingham Hospitals NHS
NHS Trust

AllergyUK

Aston University

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Coping in children and young people with food allergy.

INFORMATION SHEET FOR CHILDREN

My name is Jenny Hammond. I am a PhD student at Aston University, and I am looking at how children and young people cope with having a food allergy. I am writing to ask if you would like to help us find out more about how children and young people live with and cope with having a food allergy.

Before you decide whether you want to help us, we would like to tell you what this study is all about and why we are doing it. Please read this letter and think carefully before deciding. If you have questions or there are any bits that you do not understand please get in touch with me or ask your parents or guardian. My contact details are at the top of this letter.

What is the study about?

We are interested in finding out how children cope with having a food allergy. By asking you to tell us what it is like to have a food allergy and how you cope with having a food allergy day to day, we can then help develop a questionnaire for children of all ages to complete and this can help us understand a bit more about how children cope with their food allergy. We can then try and help children and young people who may be finding it difficult to live with their food allergy.

Why have I been invited?

You have been invited to take part in this study because you have been to the allergy clinic and have been told you have a food allergy.

Do I have to take part?

You can decide if you want to take part in the study. You don't have to, it is your choice. If you don't want to take part nobody will be upset with you. If you do decide to do the study you can stop doing it whenever you want and nobody will mind.

What will happen if I take part?

We would like you to talk us about your food allergy and how you manage to cope with it. You can either come to the University or we can come to your house. We can also talk to you over the telephone if you would like to, or by Skype. We will tape this on a special piece of equipment called a Dictaphone. We will ask you if you are happy for us to use your words when we write about the study, but your name will be removed so you won't be identified. In total, this will take up to an hour.

To say thank you for taking part in this study, you will receive a £10 bookshop or Love to Shop voucher.

What are the benefits of taking part?

By looking at how children and teenagers cope with having a food allergy, we hope to be able to develop a questionnaire that will help us understand this. We hope that this will then help people like your doctor to help children and teenagers who are finding it tricky to manage their food allergy.

What are the disadvantages of taking part?

There are no disadvantages or risks to taking part. If you decide during the interview that you want to stop or take a break, you can do this at any time.

Who will see my answers to the questions?

Only the people helping to run this study will see your answers.

What will happen to the results of the study?

The information you give us will be looked at by Jenny Hammond and Dr. Rebecca Knibb. We will also write a report of the study, which will be published. The information we collect will also be written up as part of a project called a PhD. We can send you a copy of the report if you would like them. Your name will not be in anything we publish.

Will anything about the research upset me?

There are no right or wrong answers for this study and we won't ask you anything that will upset you. But if you do get upset for any reason you can stop anytime you like and nobody will mind.

What if there is a problem?

If you are worried about anything and want to make a complaint about anything to do with this study, please speak to the research team and we will do our best to answer your questions. You can ring Dr Rebecca Knibb on [redacted] or email her on [redacted]. If she cannot help you and you still have any worries about how the study has been conducted, then you can contact the Secretary of the University Research Ethics Committee, Mr John Walter, at [redacted] or telephone [redacted].

Did anyone check this study is ok to do?

Before we are allowed to do a study it has to be checked by a group of people called a Research Ethics Committee. They check the study is fair. This study has been checked by the South West - Frenchay Ethics Committee.

What do I do next?

Talk to your mum and dad, or the person who looks after you to let them know you would like to take part. You can also talk to us if you want to take part by ringing us on the number which you will find on the bottom of this information sheet. If you want to take part, please keep this letter.

Remember:

THIS IS NOT A TEST.

THERE ARE NO RIGHT OR WRONG ANSWERS

YOU DON'T HAVE TO TAKE PART IF YOU DON'T WANT TO

THANKS FOR READING THIS LETTER ☺

Jenny Hammond (PhD Student)

Appendix 8: **Parent information sheet (interviews)**

Sandwell and West Birmingham Hospitals NHS
NHS Trust

AllergyUK

Aston University

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Coping in children and adolescents with food allergy

INFORMATION SHEET FOR PARENTS

Phase One: Scale Development

My name is Jenny Hammond. I am a PhD student at Aston University, and I am studying how children and adolescents cope with having a food allergy. I am inviting your child to take part in a study we are running with the allergy clinics in Birmingham, London and with the charity Allergy UK.

Before your child decides if they would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If anything is not clear and you would like some more information you can get in touch with me on the above number or email address. Please take your time to decide whether or not you wish to take part.

Thank you for reading this.

The purpose of the study:

Food allergy seems to be on the increase, and yet there is not much research that looks at how children and adolescents view the risk of food allergy and how they cope with it. We would like to find out how children and adolescents manage their food allergy and develop questionnaires that reliably measure coping with food allergy. We hope that this will help health care professionals develop ways in which children can be supported to manage their food allergy and the questionnaires will be able to measure whether this works.

Why has my child been invited and what would we need to do?

Your child has been invited to take part in the study because they have been to the allergy clinic and have had a food allergy diagnosis. It does not matter when your child was diagnosed, as long as they still have a food allergy and have not grown out of it. If your child would like to take part we would like to interview them about how they cope with their food allergy. For the interviews you could come to Aston University, or we could come to your house or another quiet location of your choosing. We can also do interviews over the telephone or by Skype. We will tape the interviews and will ask you if you are happy for us to use your child's words when we write about the study (with your child's name removed). In total this will take about 45 minutes to an hour.

Does my child have to take part?

No, it is up to your child to decide whether or not to take part. If they decide to take part you will be asked to keep this information sheet and to sign a consent form, which says you are happy for your child to take part. If your child decides to take part and wishes to stop the interview at any point, they may do so and withdraw (stop taking part) from the study without giving a reason.

If after taking part in the interview your child wishes to withdraw from the study, they are free to withdraw at any time up to two weeks after taking part in the interview and without giving a reason. Just contact us and we will destroy all the information you gave us.

Whether you decide to take part or not will not affect the standard of care that you or your child receives at the clinic.

What are the benefits of taking part?

By looking at how children and adolescents view their food allergy and how they cope with it, we hope to be able to develop a questionnaire that will be able to reliably measure how well your child is coping with a food allergy. We hope that this will help health care professionals develop ways in which children can be supported to manage their food allergy and the questionnaires will be able to measure whether this works.

Will my child be reimbursed for their time?

Each participating child will receive £10 in book tokens or Love to Shop vouchers. If you travel to Aston University to take part in interviews we can refund your travel and car park expenses.

What are the disadvantages of taking part?

There are no disadvantages or risks to taking part. If your child decides during the interview that they want to stop or take a break, they can do this at any time.

What will I need to do if I decide to allow my child to take part?

If your child would like to take part, please get in touch with Jenny Hammond by email on [redacted] or by phone on [redacted]. Or you can complete the tear off slip at the bottom of the clinic letter attached to the information sheet and post it to Aston University in the enclosed envelope. We will then get in touch with you to arrange an interview and send out a consent form for you to complete and return to us.

INFORMATION ABOUT THE CONDUCT OF THE STUDY

Will the information I give in this study be kept confidential?

Yes, all information collected from your child for the study will be kept strictly confidential. That means that no one outside of the research team will see any of the information you give us. Each person taking part in the study will be given a code or study number that we will use when looking at what your child has said in the interview. Information will be kept in a locked filing cabinet and on a password protected computer at Aston University for 7 years and then it will be destroyed. The procedures for handling, processing, storage and destruction of the questionnaire data collected during the study are compliant with the Data Protection Act 1998.

If your child tells us something which we feel is putting them at risk we may need to talk to you about this or to your doctor, but we will talk to you about that before we talk to anyone else.

What will happen to the results of the study?

The information your child give us will be looked at by Jenny Hammond and Dr. Rebecca Knibb. The information you provide will help us to develop a food allergy coping scale, a questionnaire that will measure how well your child is coping with their food allergy. We will also write a report of the study, which will be published. The information we collect will also be written up as part of a PhD. We can send you a copy of the report if you would like them. Your child's name will not be in anything we publish.

What if there is a problem?

If you have any concerns or complaints about anything to do with this study, please speak to the research team and we will do our best to answer your questions. You can ring Dr Rebecca Knibb on [redacted] or email her on [redacted]. If she cannot help you and you still have any worries about the way in which the study has been conducted, then you should contact the Secretary of the University Research Ethics Committee, Mr John Walter, at [redacted] or telephone [redacted].

Who has reviewed the study?

This study has been looked by the Ethics Committee at Aston University and by the South West - Frenchay NHS research. These are a group of people who check research to make sure that it protects the safety, rights, wellbeing and dignity of anyone who takes part.

Can I get more information?

If your child is interested in taking part in this study but would like some more information before you decide, please talk to Dr Rebecca Knibb or email us. Or please feel free to talk to your child's consultant at your clinic. If you would like to talk to an independent person about taking part in this study or about research in general in Psychology at Aston University please contact the Director of the Aston Research Centre for Children's and Young People's Health, Professor Helen Pattison, on [redacted]

If you would like independent advice on any aspect of this study, you can also contact the PALS (Patient Advice and Liaison Service) at the Sandwell and West Birmingham Hospitals NHS Trust 0121 507 5836

Thank you for taking time to read this information sheet.

Yours sincerely

Jenny Hammond — PhD Student

Dr Rebecca Knibb — Chief Investigator

Research Team:

Jenny Hammond (PhD Student), Dr Knibb (chief investigator/supervisor), Dr Richard Cooke (co-investigator/supervisor)

Appendix 9: **Child consent form (interviews)**

Ethics Approval Number_____

Participant ID number_____

CONSENT FORM (CHILD)

Coping in children and adolescents with food allergy

	Please initial each box
1. I have been told about this study and have had my questions answered	☐
2. I understand that I can stop at any time, without giving any reason and no one will mind.	☐
3. I understand that if I decide that I no longer want to take part in this study I can let the researcher know and they will remove my answers.	☐
4. I am happy for you to use the things I say when you write about this study and that you will not use my name	☐
5. I agree to take part in the above study.	☐

_____	_____	_____
Name of Child	Date	Signature
_____	_____	_____
Name of parent	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix 10: **Parent consent form (interviews)**

Ethics Approval Number_____

Participant ID number_____

Coping in children and adolescents with food allergy

STATEMENT OF INFORMED CONSENT FOR PARENTS OF CHILDREN AGED 8-16 YEARS

I agree for my child to participate in a research study to look at coping and develop a coping scale for children and adolescents with a food allergy. ☐

I and my child have read the study information (version 5) and know who to contact should we have any questions about participation in the study. ☐

I understand that my child's participation in the study is voluntary, and that they are free to withdraw at any time up to two weeks after taking part. We do not have to give any reasons or explanations for doing so. We have been provided with details of who to contact if we wish to withdraw. ☐

I agree for direct quotes to be used from the interview and understand that any quotes will be anonymised and my child's name will not be used in any publications from this research. ☐

I understand that relevant sections of my child's medical notes and data collected during the study may be looked at by individuals from Aston University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my child's records. ☐

I understand that all data my child provides will be kept confidential and stored securely on a password protected computer. Any hard copies of data will be stored in a locked filing cabinet. ☐

_____	_____	_____
Name of Child	Name of person giving consent for child	Relationship to child
	_____	_____
	Signature	Date
_____	_____	_____
Researcher	Signature	Date

Appendix 11: **Food allergy checklist**

Interview pro-forma for children and adolescents

(to be completed by interviewer prior to each interview)

- Participant identification number :……
- Gender of participant: Male [ ] Female [ ]
- Age of participant:……
- How many food allergies does participant have? .....
- Does participant have:

▪ Asthma	YES	[ ]	NO	[ ]
▪ Eczema	YES	[ ]	NO	[ ]
▪ Hay fever	YES	[ ]	NO	[ ]

- What is participant allergic to? *(tick as many as apply)*

▪ Peanut	[ ]	• Fish	[ ]
▪ Other nuts	[ ]	• Shellfish	[ ]
▪ Type of nuts ……		• Latex	[ ]
▪ Cow's milk	[ ]	• Tree pollen	[ ]
▪ Egg	[ ]	• Grass pollen	[ ]
▪ Soya	[ ]	• Other	[ ]
If other please specify:			

- Has participant had any allergies to foods which they can now eat?

▪ Egg	YES	[ ]	NO	[ ]
▪ Milk	YES	[ ]	NO	[ ]
▪ Other	YES	[ ]	NO	[ ]
If other please say what allergies they have outgrown:				

- What medicine do they have for their food allergy? (*tick as many as apply)*
-

▪ Antihistamines	[ ]
▪ Adrenaline injection (Emerade, Epi-Pen or JEXT)	[ ]
▪ None inhaler	[ ]

- Which of the following symptoms do they get? *(tick as many as apply)*

▪ Wheals/lumps on skin	[ ]	▪ Reflux/heartburn	[ ]
▪ Rash	[ ]	▪ Blocked up nose	[ ]
▪ Atopic dermatitis/eczema	[ ]	▪ Irritable or itchy nose	[ ]
▪ Itchy skin	[ ]	▪ Runny nose	[ ]
▪ Dry skin	[ ]	▪ Throat tightening/difficulty swallowing	[ ]
▪ Scabby skin	[ ]	▪ Breathing difficulties	[ ]
▪ Face swelling	[ ]	▪ Tight chest	[ ]
▪ Tingling/sore mouth	[ ]	▪ Asthma	[ ]
▪ Swelling of lips or tongue	[ ]	▪ Wheeze/coughing	[ ]
▪ Vomiting	[ ]	▪ Blue around the lips	[ ]
▪ Bloated stomach	[ ]	▪ Collapse/faint	[ ]
▪ Stomach pain	[ ]	▪ Other	[ ]
▪ Diarrhoea	[ ]	▪	[ ]
If other please specify:			

- Have they ever been to hospital with an allergic reaction to food?

  Yes [ ]No [ ]

- Have they seen a doctor about their food allergy/allergies?

  Yes [ ]No [ ]

- If they have seen a doctor, how did the doctor test for food allergy?

  Skin prick tests [ ]

  Blood tests [ ]

  Food challenge [ ]

  Other [ ]please state ……

Appendix 12: **Interview schedule**

QUESTION	PROMPTS
Introductions –	Do you have any brothers and sisters? Where do you go to school?
About the FA	
Tell me about your FA	How long have you been diagnosed with your food allergy? Do you remember when you were diagnosed? What type of allergy do you have? What do you have to avoid? What do you have to be careful of? Do you know what can happen if you have a reaction? Do you know what your symptoms are?
Have you ever had an allergic reaction?	Mild/severe? Do you remember what happened/why?
Medication	What do you have? (antihistamine/AAI) Do you know how to use your AAI?
Do you have medication for your FA? (Tell me more about your meds)	How does it make you feel having to carry your AAI around with you? [if they don't carry meds] what stops you from carrying it with you? Easy or difficult? Why is it easy/difficult?
Have you ever been out without your medication? Do you worry if you don't have it with you?	How did that make you feel?
Do you trust your medication works/will work?	Why? Has it ever not worked?
Do you think you would be able to use your medication if you needed to?	Why?

Staying safe	
What sort of things do you do to stay safe?	Do you feel you can manage your food allergy? Take medication/AAI with you? At all times? Read food labels before eating something? Rely on mum/dad/teachers?
Do you/your family do anything to keep you safe from having a reaction?	Is it easy/hard to do? Medication management?
Do you feel in control of your food allergy?	Why? What do you do to stay in control? Do they feel having an allergy/reaction is due to bad luck/chance?
What do you do to keep your food allergy under control at home?	Is it easy to manage at home? Do you feel safe when you're at home? Who helps you? [If child receives help] do you prefer having help, or would you rather manage it on your own? [If child manages on their own] would you prefer if you received more help with managing your allergy at home? Why? What precautions does your family have to take? Everyone have the same food?
How difficult is it to manage your FA away from home?	Is it different from being at home? Why?
How is your food allergy managed at school?/ How do you stay safe at school?	Do school take extra precautions to keep you safe?
Does it affect your time at school?	Do you feel like you get treated differently? How/why? What do you do to make it better for you? Do your friends know that you have an allergy, or do you hide it from them?
Do you ever miss out on school trips/activities because of your food allergy?	Why? Does school make allowances or have safety plans in place instead? How did that make you feel? What do you do to make it better for you?

Do you feel confident that you can manage your food allergy at school?	Why? How do you? Epi pen?
Do you worry about having an allergic reaction whilst at school?	Why? How do try to manage/cope with it?
Do you feel you have to be more careful at school?	Why? How do you manage that?
If you are on holiday, how do you manage your allergy? Does your eating habit have to change?	Why? Parent involvement? Easy/hard?
Do you worry more when you're on holiday?	Why? Does it affect how much you enjoy your holiday?
Have you ever had a reaction whilst on holiday?	Do you remember what happened? How did you/family manage it?
SECTION IN GREY FOR ADOLESCENTS	
Have you got more involved in managing your allergy as you have got older?	Why? Easy/hard? Why easy/hard? Buy own food? Parental involvement more/less?
How does having a food allergy impact on your social life with your friends?	Better/worse. How? What do you do to make it better for you? How does that impact on how you manage your allergy?
Do you ever miss out able to go to friends' houses/parties because of your food allergy?	How did that make you feel? What did you do to make it better for you? What did you do instead?
How do you look after yourself when you go out with your friends?	Medication? Planning?
Is it difficult to manage your FA when going out with friends?	Why?
Risk	
Have friends eaten foods you are allergic to in front of you? What do you do/how do you manage the situation	Why? Does it work? How does it make you feel? What if friends aren't aware of your allergy?

Do you ever feel jealous of your friends who can eat everything?	Why What do you do?
Do you ever eat foods that say, "may contain?"	Why? How often?
Do you ever eat food that you are allergic to?	Why? If so, how often?
Do you sometimes ignore your food allergy in order to be able to do things with your friends?	Why?
If your friends know about your allergy, how does it affect the type of risks you take?	Are they supportive? Do they avoid certain foods? Are they more relaxed? Do they understand?
Does their attitude affect how you feel and deal with your allergy?	How? What do you do?
Have you ever felt like ignoring that you have a food allergy so you can hang out with your friends?	Why? What did you do? How did that make you feel about your allergy? Did anything bad happen? Do you think you would do it again?
What do you think your chance is of accidentally eating something you are allergic to?	
What do you think your chance is of having a severe allergic reaction?	
FA Feelings	
How does your FA make you feel?	If you had a reaction do you think it would be serious? Do you worry about it at all? Fed up/angry/ok? Do these feelings change depending on the situation? At home/ At school/ Out with friends
How much do you worry or get upset about your FA?	What makes you feel that way?
What do you do if you are worried or upset about your FA?	Why? Does it help?
Who worries more about your FA?	Why? Why do you think it's different?

Do you ever get stressed or angry about your FA?	When does this happen?
What do you do when angry or stressed?	Why? Does it help? What do you do to make things better?
Do you find it easy to talk about your food allergy?	Who is it easier to talk to?
Do you speak to someone if you are finding it hard to manage your allergy?	Why Who? Does it help?
Do you use social media help you manage your food allergy?	Facebook Online discussion groups
Are you a member of a support group or charity such as Allergy UK or the Anaphylaxis Campaign?	[Provide web address for both if requested by participant]
Is there anything else you want to talk about or tell me about?	

Appendix 13: **Strategies identified within quotes (children)**

Control-based model of coping	Coping strategies identified – Elliot/10yrs
Primary-control coping	
Active coping	Yeah, I generally feel safe at my friend's house, but it's like, it's not like home where I know having a reaction isn't going to happen. It could happen at my friends, so I'll take my EpiPen with me just in case.
Vigilance	I have to look around and make sure my food doesn't mix with my friend's food and things like that, so I don't have a reaction and make sure I don't touch somebody's food by accident.
Problem solving (self-educating)	There's this website, I can't remember what it's called but it's for children with allergies and it has these tips and tricks on how to look after your allergy better and it tells you about your allergy and stuff and its really good. I've used some of the stuff they've mentioned, like having a special clip holder for my EpiPen for my school bag which will make it easier for secondary school.
Social support	The school had this person we can go talk to. So, like when he came round I asked him "could we talk?" because I thought it would be a good idea.
Secondary-control coping	
Social comparisons	Someone in the class above me had really bad eczema and you could see it on her arms and legs so I think I'm ok because you can't see my allergies really and no one stares.
Disengagement coping	
Avoidance	I don't like showing it because like, so I used to say, 'Oh it's just my lunch in here', but like yeah don't like showing it, so I try and hide it so I just look normal like. So, I try and hide it so I just look normal like. So, say my friends offered me something like, I don't know, peanuts or something and I'd just say I wasn't hungry rather than oh I'm allergic to it.

Appendix 14: Strategies identified within quotes – children combined

Control-based model of coping	Coping strategies identified within quotes
Primary-control coping	
Active coping	Yeah, I generally feel safe at my friend's house, but it's like, it's not like home where I know having a reaction isn't going to happen. It could happen at my friends, so I'll take my EpiPen with me just in case." – **Elliot /10yrs**
Social support	Mums always carried the EpiPen when we go out.– **Hannah/9yrs** Normally I'll get mum to check for me to make sure its ok – **Jasmine/9yrs**
Secondary-control coping	
Positive thinking	So, I sometimes think it's not all that bad when I can eat some of my favourite foods and still do things I like.- Hannah /9yrs I could be allergic to so much more stuff and I'm not so it's not that bad really. – Francis/10yrs
Social comparisons	So, I think that would be worse than being allergic to peanuts- Francis 10/yrs Someone in the class above me had really bad eczema and you could see it on her arms and legs so I think I'm ok because you can't see my allergies really and no one stares. – **Elliot /10yrs**
Disengagement coping	
Avoidance	I don't go to birthday parties because in case the food isn't safe and there'll be lots of other children there and it could dangerous – **Jasmine/9yrs** I don't really want to talk about my allergies with my friend's because I don't want the attention for them to think I'm like always ill or something. **– Jacob/11yrs**
Minimisation	So, I try and hide it, so I just look normal like – **Elliot/10yrs**

Appendix 15: **Adolescent information sheet**

Sandwell and West Birmingham Hospitals NHS
NHS Trust

AllergyUK

Aston University

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Coping in Children and Adolescents with Food Allergy

INFORMATION SHEET FOR TEENAGERS

My name is Jenny Hammond. I am a PhD student at Aston University, and I am studying how children and adolescents cope with having a food allergy. We are inviting you to take part in a study we are running with the allergy clinics in Birmingham and with the charity Allergy UK.

Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If anything is not clear and you would like some more information you can get in touch with me on the above number or email address. Please take your time to decide whether or not you wish to take part.

Thank you for reading this.

The purpose of the study:

Food allergy seems to be on the increase, and yet there is not much research that looks at how children and adolescents view the risk of food allergy and how they cope with it. So we can develop ways in which we can help children and teenagers manage their food allergy, it is important to understand what they do to manage and how they cope with it. We can then develop questionnaires that reliably measure this and find ways to help them manage better.

Why have I been invited and what would I need to do?

You have been invited to take part in the study because you have been to the allergy clinic and have had a food allergy diagnosis. If you would like to take part we would like to interview you about how you cope with your food allergy. For the interviews you could come to Aston University, or we could come to your house or another quiet location of your choosing. We can also do interviews over the telephone or by Skype. We will tape the interviews and will ask you if you are happy for us to use your words when we write about the study (with your name removed). In total this will take about 45 minutes to an hour. To thank you for taking part in this study, you will receive a £10 bookshop or Love to Shop voucher that you can spend in a large number of shops.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you will be asked to keep this information sheet and to sign a consent form, which says you are happy to take part. If you decide to take part you are free to withdraw (stop taking part in the study) at any time up to two weeks after taking part and without giving a reason. If you do take part in the study and you change your mind afterwards, you can just contact us and we will destroy all the information you gave us.

What are the benefits of taking part?

By looking at how children and teenagers cope with having a food allergy, we hope to be able to develop a questionnaire that will help us understand this. We hope that this will then help us to help children and teenagers who are finding it tricky to manage their food allergy.

What are the disadvantages of taking part?

There are no disadvantages or risks to taking part. If you decide during the interview that you want to stop or take a break, you can do this at any time.

Will the information I give in this study be kept confidential?

Yes, all information collected from you for the study will be kept strictly confidential. That means that no one outside of the research team will see any of the information you give us. Each person taking part in the study will be given a code or study number that we will use when looking at what you have said in the interview. Information will be kept in a locked filing cabinet and on a password protected computer at Aston University for 7 years and then it will be destroyed.

If you tells us something which we feel is putting yourself in danger for your health we may need to talk to you about this or to your parents, but we will talk to you about that before we talk to anyone else.

What will happen to the results of the study?

The information you give us will be looked at by Jenny Hammond and Dr Rebecca Knibb. From looking at this we will be able to develop a food allergy coping questionnaire. We will also write a report of the study, which will be published. The information we collect will also be written up as part of a PhD. We can send you a copy of the report if you would like them. Your name will not be in anything we publish.

What if there is a problem?

If you are worried about anything and want to make a complaint about anything to do with this study, please speak to the research team and we will do our best to answer your questions. You can ring Dr Rebecca Knibb on [redacted] or email her on [redacted]. If she cannot help you and you still have any worries about the way in which the study has been conducted, then you should contact the Secretary of the University Research Ethics Committee, Mr John Walter, at [redacted] telephone [redacted].

Who has reviewed the study?

This study has been looked by the Ethics Committee at Aston University and by the South West - Frenchay NHS research. These are a group of people who check research to make sure that it protects the safety, rights, wellbeing and dignity of anyone who takes part.

Can I get more information?

If you are interested in taking part in this study but would like some more information before you decide, please talk to Dr Rebecca Knibb or email us. Or please feel free to talk to your consultant at your clinic. If you would like to talk to an independent person about taking part in this study or about research in general in Psychology at Aston University please contact the Director of the Aston Research Centre for Children's and Young People's Health, Professor Helen Pattison, on [redacted].

If you would like independent advice on any aspect of this study, you can also contact the PALS (Patient Advice and Liaison Service) at the Sandwell and West Birmingham Hospitals NHS Trust 0121 507 5836

If I decide to take part what do I do now?

If you do decide to take part in this study, thank you very much. Please let your parents/guardian know that you want to take part and they can contact us. There is a tear off slip attached to the clinic letter for them to complete and send back to us. We can then arrange a date for you to take part. Please keep a copy of this information sheet.

Thank you for taking time to read this information sheet.

Yours sincerely

Jenny Hammond — Dr Rebecca Knibb

PhD Student — Chief Investigator

Research Team:

Jenny Hammond (PhD Student), Dr Knibb (chief investigator/supervisor), Dr Richard Cooke (co-investigator/supervisor)

Appendix 16: **Adolescent consent form**

Ethics Approval Number_____

Participant ID number_____

Coping in children and adolescents with food allergy

STATEMENT OF INFORMED CONSENT (ADOLESCENTS)

Please initial each box to indicate you have read the statement:

I agree to participate in a research study looking at coping and developing a coping scale for children and adolescents with a food allergy. ☐

I have read the study information (version4) and know who to contact should I have any questions about my participation in the study. ☐

I understand that my participation in the study is voluntary, and that I am free to withdraw at any time up to two weeks after taking part. I do not have to give any reasons or explanations for doing so. I have been provided with details of who I should contact if I wish to withdraw. ☐

I agree for direct quotes to be used from the interview and understand that any quotes will be anonymised and my name will not be used in any publications from this research. ☐

I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from Aston University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

I understand that all data I provide will be kept confidential and stored securely on a password protected computer. Any hard copies of data will be stored in a locked filing cabinet. ☐

OPTIONAL I am happy to be contacted again about this research study. ☐

_____	_____	_____
Name of Participant	Signature	Date
_____	_____	_____
Researcher	Signature	Date

Appendix 17: **Strategies within quotes (adolescents)**

Control-based model of coping	Coping strategies identified – Adam/15yrs
Primary-control coping	
Social support	Yeah when I'm feeling like that, sometimes I'll go talk to my mum and dad about it Uhmm well I normally let my mum or dad ask for the allergy menu so I don't have to cause a fuss because it can be hassle
Secondary-control coping	None used
Disengagement coping	
Avoidance	Sometimes I have like science and English and sports on the same day, which is a lot of stuff for me to have in my bags, and then my sports bag too. So, I have sometimes, not like loads, only a few times, left my EpiPen at home because I can't fit it in my bag. But I'll be extra careful with food and things and I'm pretty sure the school would have a spare pen in the nurse's office anyway Sometimes I'll eat my lunch somewhere else because I worry, and I don't want to make a thing out of it. Sometimes I just think I can't be bothered to go out because its extra effort'
Minimisation	I try to just pretend that I don't have an allergy, that I'm normal I just try to avoid talking about it with them (friends) and act like I don't have it

Appendix 18: Strategies identified within quotes – adolescents combined

Control-based model of coping	Coping strategies identified
Primary-control coping *Social support*	Yeah when I'm feeling like that, sometimes I'll go talk to my mum and dad about it – **Adam/15yrs**
	Uhmm well I normally let my mum or dad ask for the allergy menu so I don't have to cause a fuss because it can be hassle – **Adam/15yrs**
	She reminds me to check my bag– **Vijay /15yrs**
Active coping (vigilance)	It's still the same thing I have to do no matter where I go, like actually, probably, uhmm I have to do more of it, like check labels more, check menu's more, check the tables more and things like that – **Amelia/16yrs**
	I do the checking now, I ask what's in the food, tell them about my allergies – **Harry/15yrs**
Secondary-control coping Social comparisons	It's just peanuts and I'd rather be someone who's allergic to nuts than something else like dairy, I think that one's a bit more unknown - **Rachel/13yrs**
Positive reinterpretation	It could be worse, like, I think it would be worse to be diabetic because you would always have to be injecting yourself and I think that would make it really difficult and make you really stand out. – **Alice/15yrs**
	I don't see myself as different, I can still go out with them, I can still go to school, I can still go to Costas [sic] with them – **Rory/12yrs**
Disengagement coping *Avoidance*	Sometimes I'll eat my lunch somewhere else because I worry and I don't want to make a thing out of it. – **Adam/15yrs**
	I just try to avoid talking about it with them (friends) and act like I don't have it – **Adam/15** yrs
	I just don't really go out with them if they're going somewhere to eat – **Helen/16yrs**

Appendix 19: **Grouping quotes into categories**

Category: Medication	**Quote**
Medication	"yeah I think I'd be able to use it, but I'd probably prefer mum to do it". – Farina (9yrs) "If I'm going to my friend's house, he only lives down the road from me, I won't really bother to carry my EpiPen on me because it's normally fine when I go there so I don't need it, I feel like I can manage it fine there" – Francis (10yrs) "Uhmm, I after 7 years I still can't remember it and I still forget it and my mums always like have you got your EpiPen on you? And I always have to go and get it because I forget to pack it because she like always took care of it for me" – Kirsty (14yrs)
Parental support	"It's just part of growing up, I guess. My mum does less with my food allergy now and I do more for it, but I do more stuff now for myself anyway like when I'm at school or out with my friends, I'm more independent now". Alice (15yrs) "I'd rather someone else or my mum or someone do it for me because I don't know how to do it" – Callum (11yrs)

Appendix 20: **Splitting categories**

Category: Medication	**Quote**
Carrying medication	"Yeah, I generally feel safe at my friend's house, but it's like, it's not like home where I know having a reaction isn't going to happen. It could happen at my friends, so I'll take my EpiPen with me just in case." "I always carry my EpiPen out with me"
Not carrying medication	"If I'm going to my friend's house, he only lives down the road from me, I won't really bother to carry my EpiPen on me because it's normally fine when I go there so I don't need it, I feel like I can manage it fine there" "My EpiPen is too big to fit in my pockets, so it's just better if my mum carries it for me." "Mums always carried the EpiPen when we go out."

Appendix 21: **Version 1 CS-FA**

PILOT FOOD ALLERGY COPING SCALE V.1

These questions are about how you cope with your food allergy. Please try to answer the questions on your own. You can ask your parents for help if you need to. There is no right or wrong answer!

For each of the questions below, circle the response that best describes how you feel about the statement. 1 = Never, 2= Not very often, 3 = Sometimes, 4 = Most of the time, 5 = Always

	Never	Not very often	Sometimes	Most of the time	Always
1. I carry my medication with me in case I have an allergic reaction.	1	2	3	4	5
2. I use a plan to help me remember to carry my medication.	1	2	3	4	5
3. I only carry my medication with me if I am going somewhere I am unfamiliar with.	1	2	3	4	5
4. I constantly check around me to make sure there are no foods near me.	1	2	3	4	5
5. I sit separately from others when eating, because I worry about having an allergic reaction.	1	2	3	4	5
6. I check the food labels on everything that I eat to make sure that it is safe.	1	2	3	4	5
7. If I can't eat something, I look for an alternative to eat.	1	2	3	4	5
8. I am more careful with my food allergy outside of my home (e.g. at school or on holiday.)	1	2	3	4	5
9. If eating out at a restaurant, I ask for the food allergy menu.	1	2	3	4	5
10. I eat food even if I am unsure of its content.	1	2	3	4	5
11. I don't eat food that has been offered to me, in case I have an allergic reaction.	1	2	3	4	5
12. I eat foods that I know are unsafe for me.	1	2	3	4	5
13. If I want to know about my food allergy, I find the information myself.	1	2	3	4	5

14. If I want to know more about my food allergy, I ask somebody.	1	2	3	4	5
15. I rely on my parents to carry my medication for me.	1	2	3	4	5
16. I check with my parents to make sure my food is safe for me to eat.	1	2	3	4	5
17. When eating out, I prefer my parents to ask for the food allergy menu.	1	2	3	4	5
18. I ask my friends to help me with my food allergy.	1	2	3	4	5
19. I avoid talking to my friends about my food allergy.	1	2	3	4	5
20. If I am having an allergic reaction, I prefer having someone else to administer my medication.	1	2	3	4	5
21. I avoid social events e.g. birthday parties, because of my food allergy.	1	2	3	4	5
22. I avoid socialising with my friends because of my food allergy.	1	2	3	4	5
23. I teach my friends about my food allergy and my medication.	1	2	3	4	5
24. I tell people about my food allergy to stay safe.	1	2	3	4	5
25. If I feel upset about my food allergy, I speak to my parents about it.	1	2	3	4	5
26. If I feel upset about my food allergy, I become distressed (e.g. cry).	1	2	3	4	5
27. If I feel angry about my food allergy, I speak to my parents about it.	1	2	3	4	5
28. If I feel angry about my food allergy, I become frustrated (e.g. shout).	1	2	3	4	5
29. If I'm feeling upset about my food allergy, I distract myself with something (e.g. watch TV).	1	2	3	4	5

30. If I'm feeling angry about my food allergy, I distract myself with something (e.g. watch TV).	1	2	3	4	5
31. I do things I enjoy, to take my mind off my food allergy (e.g. a hobby).	1	2	3	4	5
32. I think to myself "things could be worse" when I think about my food allergy.	1	2	3	4	5
33. If I'm worried about my food allergy, I ask for help.	1	2	3	4	5
34. I joke about my food allergy, to make me feel better.	1	2	3	4	5
35. I hide my food allergy from other people.	1	2	3	4	5
IF YOU ARE AGED 12-16, PLEASE CONTINUE AND ANSWER THE QUESTIONS BELOW					
36. When I go out with my friends, I take my medication out with me to stay safe.	1	2	3	4	5
37. I ignore my food allergy so I can do more things with my friends.	1	2	3	4	5
38. when I go out to eat with my friends, I inform staff of my food allergy.	1	2	3	4	5
39. When I go out to eat with my friends, I avoid foods that could give me an allergic reaction.	1	2	3	4	5
40. When I go out to eat with my friends, I tell them if I cannot eat the food there.	1	2	3	4	5
41. When I go out with my friends, I am less careful with my food allergy.	1	2	3	4	5

Appendix 22: **Changes made to the CS-FA**

Prototype CS-FA	Comments	Suggestions
1. I carry my medication with me in case I have an allergic reaction.	Too broad	Separate questions for EpiPen and antihistamines. And free text question to explain why they don't always carry their medication.
2. I use a plan to help me remember to carry my medication.	Keep as is	
3. I only carry my medication with me if I am going somewhere, I am unfamiliar with.	A little hard for younger children to understand	Reword. "I only carry my medication with me if I'm going somewhere, I've not been before."
4. I constantly check around me to make sure there are no foods near me.	Complex wording	Remove 'constantly' – "I check that there are no foods around me that I could be allergic to"
5. I sit separately from others when eating, because I worry about having an allergic reaction.	Complex wording	Simplify – I avoid eating….
6. I check the food labels on everything that I eat to make sure that it is safe.	Could be made clearer, when are labels being checked?	Expand – "before eating"
7. If I can't eat something, I look for an alternative to eat.	Remove	
8. I am more careful with my food allergy outside of my home (e.g. at school or on holiday.)	Too broad.	Simplify this question, and have separate questions for school. "I am more careful about my food allergy when I'm in a place that I'm not used to."
9. If eating out at a restaurant, I ask for the food allergy menu.	Keep as is	
10. I eat food even if I am unsure of its content.	Rephrase, make it explicit it is food containing an allergen	Change to "I eat food which may contain an allergen that I'm allergic to."
11. I don't eat food that has been offered to me, in case I have an allergic reaction.	Remove – already have a question regarding risk, eating an allergen	
12. I eat foods that I know are unsafe for me.	Remove – similar question once question 10 is rephrased	
13. If I want to know about my food allergy, I find the information myself.	Keep as is	
14. If I want to know more about my food allergy, I ask somebody.	Needs clarification of source	Put in examples, e.g. parents, teachers, friends
15. I rely on my parents to carry my medication for me.		Suggest the words mum or dad in place of parents

16. I check with my parents to make sure my food is safe for me to eat.	Simplify the wording	Suggest "I check with my mum or dad if my food is safe to eat"
17. When eating out, I prefer my parents to ask for the food allergy menu.	Simplify the wording, make it more explicit what the question is asking.	Use 'somebody else' – child/adolescent may not always be with parents. When going out for a meal, I prefer it if somebody else (e.g. Mum or Dad) checks what ingredients are in the food.
18. I ask my friends to help me with my food allergy.	Too complex – what are friends helping with?	Clarify – "I ask my friends to help me avoid foods that I'm allergic to."
19. I avoid talking to my friends about my food allergy.	Keep as is	
20. If I am having an allergic reaction, I prefer having someone else to administer my medication.	Make the questions clearer	Suggest "If I need to use my adrenaline auto-injector (e.g. EpiPen, JEXT), I prefer someone else to do it for me." – not use mum or dad, could be in the company of someone else
21. I avoid social events e.g. birthday parties, because of my food allergy.	Add in other types of social events	Add in school trips
22. I avoid socialising with my friends because of my food allergy.	Felt to be too similar to Q21.	Remove
23. I teach my friends about my food allergy and my medication.	Keep as is	
24. I tell people about my food allergy to stay safe.	Keep as is	
25. If I feel upset about my food allergy, I speak to my parents about it.	Comment from professionals: a parent might not always be present/available	Suggest remove 'parent' replace with 'someone close to me'
26. If I feel upset about my food allergy, I become distressed (e.g. cry).	The word distress was difficult to understand.	Remove
27. If I feel angry about my food allergy, I speak to my parents about it.	Comment from professionals: a parent might not always be present/available	Suggest remove 'parent' replace with 'someone close to me'
28. If I feel angry about my food allergy, I become frustrated (e.g. shout).	All commented that they wouldn't 'shout', thought question was irrelevant	Remove
29. If I'm feeling upset about my food allergy, I distract myself with something (e.g. watch TV).	Comments from both participants and professionals: question not very clear.	"If I'm feeling upset about my food allergy, I distract myself by doing things that I like."
30. If I'm feeling angry about my food allergy, I distract myself with something (e.g. watch TV).	Comments from both participants and professionals: question not very clear.	"If I'm feeling angry about my food allergy, I distract myself by doing things that I like"

31. I do things I enjoy, to take my mind off my food allergy (e.g. a hobby).	Suggest combining the wording of this question with Q29 and 30	Remove
32. I think to myself "things could be worse" when I think about my food allergy.	Comment from professionals: what does this strategy do, expand on the effect of its use	Suggest adding replacing "when I think about my food allergy" with "to feel better about my food allergy"
33. If I'm worried about my food allergy, I ask for help.	Make the questions clearer, who are they asking for help?	Suggest "If I feel worried about my food allergy, I speak to somebody (e.g. parents, teachers, friends) about it"
34. I joke about my food allergy, to make me feel better.	Keep as is	
35. I hide my food allergy from other people.	Expand on this question – why would they hide their allergy?	Suggest adding "because I don't want them to know about it."
Questions for 12-16-year olds		
36. When I go out with my friends, I take my medication out with me to stay safe.	This could be a question for children, not only adolescents	Make this a core question – or, make this question optional for all ages.
37. I ignore my food allergy so I can do more things with my friends.	This could be a question for children, not only adolescents	Make this a core question, expand on wording further. Suggest "I ignore my food allergy so I can do things with my friends that I normally wouldn't be able to do."
38. when I go out to eat with my friends, I inform staff of my food allergy.	The word inform may be too complex	Replace inform with 'tell' – make this an optional question for all ages
39. When I go out to eat with my friends, I avoid foods that could give me an allergic reaction.	Wording fine, but possibly applicable to children	Make this question optional for all ages
40. When I go out to eat with my friends, I tell them if I cannot eat the food there.	Adolescents felt this wouldn't apply to everyone	Remove
41. When I go out with my friends, I am less careful with my food allergy.	Adolescents felt this question wasn't clear. Why would they be less careful?	Make this question optional for all ages
Additional questions suggested		
I won't use my medication if other people are around me. When I eat at school, I make sure that I'm not near any food that could give me an allergic reaction. When buying food at a shop, I try to look for something that is safe for me to eat. I rely on my Mum or Dad to check food labels for me. If I'm offered food that I'm unsure about, I read the label or ask about the ingredients, to check if it's safe to eat. When I'm at school, I don't eat with my friends in case I have an allergic reaction. I eat the same foods as my friends, so I don't feel left out, even if I know I'm allergic to it. When I'm with my friends, I'm less careful about my food allergy, because I don't want to be different. If my friends are going out for a meal, I won't go with them.		

Appendix 23: **Prototype CS-FA**

Prototype Coping Scale for Food Allergy (CS-FA)

These questions are about how you cope with your food allergy. Please try to answer the questions on your own. You can ask your parents for help if you need to. There is no right or wrong answer!

For each of the questions below, circle the response that best describes how you feel about the statement.

1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Most of the time, 5 = Always

	Never	Rarely	Sometimes	Most of the time	Always
1. I carry my antihistamines with me in case I have an allergic reaction.	1	2	3	4	5
If you don't always carry your antihistamines with you, please explain why:					
2. I carry my adrenaline auto-injector (e.g. EpiPen, Jext) with me in case I have an allergic reaction.	1	2	3	4	5
If you don't always carry your adrenaline auto-injector with you, please explain why:					
3. I use a plan to help me remember to carry my medication.	1	2	3	4	5
4. I only carry my medication with me if I'm going somewhere I've not been before.	1	2	3	4	5
5. I check that there are no foods around me that I could be allergic to.	1	2	3	4	5
6. I avoid eating with other people, because I worry about having an allergic reaction.	1	2	3	4	5
7. Before eating, I check the food labels to make sure the food is safe for me to eat.	1	2	3	4	5
8. I rely on my Mum or Dad to check food labels for me.	1	2	3	4	5
9. When buying food at a shop, I try to look for something that is safe for me to eat.	1	2	3	4	5
10. When going out for a meal, I ask what ingredients are in the food.	1	2	3	4	5
11. When I eat at school, I make sure that I'm not near any food that could give me an allergic reaction.	1	2	3	4	5

12. I won't use my medication if other people are around me.	1	2	3	4	5
13. I eat food which may contain an allergen that I'm allergic to.	1	2	3	4	5
14. If I'm offered food that I'm unsure about, I read the label or ask about the ingredients, to check if it's safe to eat.	1	2	3	4	5
15. If I want to know more about my food allergy, I find the information myself.	1	2	3	4	5
16. If I want to know more about my food allergy, I ask somebody (e.g. parents, teachers, friends) for more information.	1	2	3	4	5
17. I rely on my Mum or Dad to carry my medication for me.	1	2	3	4	5
18. If I feel upset about my food allergy, I prefer to be by myself.	1	2	3	4	5
19. If I feel angry about my food allergy, I prefer to be by myself.	1	2	3	4	5
20. I ask my Mum or Dad if my food is safe to eat.	1	2	3	4	5
21. When going out for a meal, I prefer it if somebody else (e.g. Mum or Dad) checks what ingredients are in the food.	1	2	3	4	5
22. When I'm at school, I am less careful about my food allergy.	1	2	3	4	5
23. I ask my friends to help me avoid foods that I'm allergic to.	1	2	3	4	5
24. I avoid talking to my friends about my food allergy.	1	2	3	4	5
25. If I need to use my adrenaline auto-injector (e.g. EpiPen, JEXT), I prefer someone else to do it for me.	1	2	3	4	5
26. I avoid social events (e.g. birthday parties or school trips), because of my food allergy.	1	2	3	4	5
27. I teach my friends about my food allergy and my medication.	1	2	3	4	5

28. I tell people about my food allergy to stay safe.	1	2	3	4	5
29. If I feel upset about my food allergy, I talk to someone close to me about it.	1	2	3	4	5
30. If I feel angry about my food allergy, I talk to someone close to me about it.	1	2	3	4	5
31. I think to myself, "things could be worse," to feel better about my food allergy.	1	2	3	4	5
32. I compare myself to others, to feel better about my food allergy.	1	2	3	4	5
33. If I'm feeling upset about my food allergy, I distract myself by doing things that I like.	1	2	3	4	5
34. If I'm feeling angry about my food allergy, I distract myself by doing things that I like.	1	2	3	4	5
35. I look for the positives about my food allergy to help me feel better.	1	2	3	4	5
36. If I feel worried about my food allergy, I speak to somebody (e.g. parents, teachers, friends) about it.	1	2	3	4	5
37. I joke about my food allergy, to feel better about it.	1	2	3	4	5
38. I hide the fact I have a food allergy from other people, because I don't want them to know about it.	1	2	3	4	5
39. When I'm with my friends, I'm less careful about my food allergy, because I don't want to be different.	1	2	3	4	5
40. I eat the same foods as my friends so I don't feel left out, even if I know I'm allergic to it.	1	2	3	4	5
41. I ignore my food allergy so I can do things with my friends that I normally wouldn't be able to do.	1	2	3	4	5
42. I am more careful about my food allergy when I'm in a place that I'm not used to.	1	2	3	4	5
43. When I'm at school, I don't eat with my friends in case I have an allergic reaction.	1	2	3	4	5

The following questions are about going out without any adults. If you always go out with an adult, please go to the final question.					
44. When I go out with my friends, I take my medication with me to stay safe.	1	2	3	4	5
45. When I go out for a meal with my friends, I tell staff about my food allergy.	1	2	3	4	5
46. When I go out for a meal with my friends, I avoid foods that could give me an allergic reaction.	1	2	3	4	5
47. When I go out for a meal with my friends, I tell my friends if I cannot eat the food there.	1	2	3	4	5
48. When I go out with my friends, I am less careful about my food allergy.	1	2	3	4	5
49. If my friends are going out for a meal, I won't go with them.	1	2	3	4	5
Is there anything else that you do to cope with your food allergy? If so, please write it below:					
Write your answer here:					

Appendix 24: **Child information sheet (CS-FA)**

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Coping in children and adolescents with food allergy

Phase Two: Scale reliability and validity

INFORMATION SHEET FOR CHILDREN

My name is Jenny Hammond. I am a PhD student at Aston University, and I am looking at how children and young people cope with having a food allergy. I am writing to ask if you would like to help us find out more about how children and young people live with and cope with having a food allergy.

Before you decide whether you want to help us, we would like to tell you what this study is all about and why we are doing it. Please read this letter and think carefully before deciding. If you have questions or there are any bits that you do not understand please get in touch with me or ask your mum or dad.

What is the study about?

We are interested in finding out how children cope with having a food allergy. We asked many children and teenagers like you about how they cope with a food allergy in a questionnaire. We would like you to complete a shorter version to see if the questionnaire works properly. There are two questionnaire's to complete and should not take longer than 15 minutes.

Why have I been invited?

You have been invited to take part in this study because you previously completed some questionnaires about how you cope with food allergy.

Do I have to take part?

You can decide if you want to take part in the study. You don't have to; it is your choice. If you don't want to take part nobody will be upset with you. If you do decide to do the study you can stop doing it whenever you want and nobody will mind.

What will happen if I take part?

We would like you to complete a questionnaire about how you cope with your food allergy. There is only two questionnaire's and should not take longer than 15 minutes. You will be emailed the short coping questionnaire to complete again in 2 weeks' time. This allows us to check if the coping questionnaire is working correctly. There will only be one questionnaire to complete the second time round, and should not take longer than 10 minutes to complete.

Who will see my answers to the questions?

Only the people helping to run this study will see your answers.

Will anything about the research upset me?

There are no right or wrong answers for this study and we won't ask you anything that will upset you. But if you do get upset for any reason you can stop anytime you like and nobody will mind.

Did anyone check this study is ok to do?

Before we are allowed to do a study it has to be checked by a group of people called a Research Ethics Committee. They check the study is fair. This study has been checked by the South West and Frenchay Ethics Committee.

What do I do next?

Talk to your mum and dad or the person who looks after you to let them know you would like to take part. You can also talk to us if you want to take part by ringing us on the number at the top of this information sheet. If you want to take part, you can complete the questionnaires online or, we can send the questionnaires out to you to complete. If you want to take part, please keep this letter.

Remember:

THIS IS NOT A TEST.

THERE ARE NO RIGHT OR WRONG ANSWERS

YOU DON'T HAVE TO TAKE PART IF YOU DON'T WANT TO

THANK YOU FOR READING THIS LETTER ☺

Jenny Hammond (PhD Student)

Appendix 25: **Adolescent information sheet (CS-FA)**

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Coping in children and adolescents with food allergy

Phase Two: Scale reliability and validity

INFORMATION SHEET FOR TEENAGERS

My name is Jenny Hammond. I am a PhD student at Aston University, and I am studying how children and adolescents cope with having a food allergy. You are being invited to take part in a research study to develop some coping questionnaires for people like you with a food allergy.

Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read this information carefully and discuss it with others if you wish to. If anything is not clear and you require more information before you decide whether or not you should take part in the study, please contact a member of the study team (details at end of information sheet).

Thank you for reading this.

The purpose of the study:

Food allergy seems to be on the increase, and yet there is not much research that looks at how children and teenagers view the risk of food allergy and how they cope with it. So we can develop ways in which we can help children and teenagers manage their food allergy, it is important to understand what they do in order to cope with having a food allergy. There are no questionnaires currently available that can measure the way in which children and teenagers cope with their food allergy.

In order to develop these questionnaires, the research team interviewed children and teenagers like you, who suffer from a food allergy, about how having a food allergy affects them and how they cope with it. We developed a prototype questionnaire which you completed, alongside other questionnaires. We are now asking you to complete the short version of the coping questionnaire along with one other questionnaire. This should take no longer than 15 minutes to complete.

Why have I been invited and what would I need to do?

You have been invited to take part in the study because you previously completed questionnaires for the research team about how you cope with food allergy, and indicated that you were happy to be contacted again about the study.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part, you are free to withdraw (stop taking part in the study) at any time without giving a reason. If you do take part in the study and within two weeks you change your mind, you can just contact us and we will destroy all the information you gave us.

What are the disadvantages or risks of taking part?

You may feel upset answering questions about how your food allergy has affected you. You will be able to stop answering questions at any time you wish and either take a break or decide you do not want to take part anymore. If there are any questions you don't want to answer you can leave them blank.

What do I need to do if I decide to take part?

Please complete a consent form and the questionnaire's online. If you have complete the questionnaire, you will be emailed the short coping questionnaire to complete again in two weeks' time. This allows us to check if the coping questionnaire is working correctly. There will only be on questionnaire to complete the second time round, and should take no longer than 10 minutes to complete.

Will the information I give in this study be kept confidential?

Yes, all information collected from you will be kept strictly confidential. That means that no one outside of the research team will see any of the information you give us. Each person taking part in the study will be given a code or study number that we will use when looking at the information from the study. Information will be kept in a locked filing cabinet and on a password protected computer at Aston University for 7 years and then it will be destroyed.

What will happen to the results of the study?

The information you give us will be looked at by Jenny Hammond and Dr. Rebecca Knibb. We will be able to make sure that the coping questionnaires we have are reliable and valid, that is they measure what we think they measure and will be useful for you and for your doctor. We will write a report of the study which will be published and the results will be written up as part of a PhD. We can send you a summary of the results if you would like them. Your name will not be in anything we publish. The questionnaires will then be available for use by you and your doctor.

What if there is a problem?

If you are worried about anything to do with this study, please speak to the research team and we will do our best to answer your questions. You can ring Dr Rebecca Knibb or email her (phone number and email address are at the bottom of this information sheet). If she cannot help you and you still have any worries about the way in which the study has been conducted, then you should contact the Secretary of the University Research Ethics Committee, Mr John Walter, at [redacted] or telephone [redacted]

Who has reviewed the study?

This study has been looked by the Ethics Committee at Aston University and by the South West and Frenchay Ethics Committee. These are a group of people who check research to make sure that it protects the safety, rights, wellbeing and dignity of anyone who takes part.

Can I get more information?

If you are interested in taking part in this study but would like some more information before you decide, please talk to Dr Rebecca Knibb or email us. Or please feel free to talk to the person who looks after you, such as your mum or dad. If you would like to talk to an independent person about taking part in this study or about research in general in Psychology at Aston University please contact the Director of the Aston Research Centre for Children's and Young People's Health, Professor Helen Pattison, on [redacted].

If you would like independent advice on any aspect of this study, you can also contact the PALS (Patient Advice and Liaison Service) at the Sandwell and West Birmingham Hospitals NHS Trust 0121 507 5836

Thank you for taking time to read this information sheet.

Yours sincerely

Jenny Hammond	Dr Rebecca Knibb
PhD Student	Chief Investigator

Research Team:

Jenny Hammond (PhD Student), Dr Knibb (chief investigator/supervisor), Dr Richard Cooke (co-investigator/supervisor)

Appendix 26: **Parent information sheet (CS-FA)**

School of Life and Health Sciences
Aston University
Aston Triangle
Birmingham
B4 7ET
[redacted]

Coping in children and adolescents with food allergy

Phase Two: Scale reliability and validity

INFORMATION SHEET FOR PARENTS

My name is Jenny Hammond. I am a PhD student at Aston University, and I am studying how children and adolescents cope with having a food allergy. I am inviting your child to take part in a study we are running with the allergy clinics in Birmingham and with the charity Allergy UK.

We have developed a questionnaire that measures how well children cope with food allergy and are asking children and adolescents in the UK to fill them in for us. Before you decide whether you wish for your child to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read this information carefully and discuss it with others if you wish. If anything is not clear and you require more information before you decide whether or not your child should take part in the study, please contact a member of the study team (details at end of information sheet).

Thank you for reading this.

The purpose of the study:

Food allergy seems to be on the increase, and yet there is not much research that looks at how children and adolescents view the risk of food allergy and how they cope with it. In order to develop ways in which we can help children manage their food allergy it is important to understand what they do to manage their food allergy and how they cope with it. There are no questionnaires currently available that can measure the way in which children and adolescents cope with their food allergy.

In order to develop these questionnaire, the research team interviewed children and adolescents who suffer from a food allergy about how having a food allergy affects them and how they cope with it. We developed a prototype questionnaire and asked children and adolescents with a food allergy in the UK to complete this. We are now asking children and adolescents who previously completed the prototype questionnaire, to complete the final version so we can see if the questionnaire works properly. This should take your child no longer than 15 minutes to complete.

Why has my child been invited and what would we need to do?

Your child has been invited to take part in the study as they previously completed the prototype questionnaire and because they indicated that they were happy to be contacted again about the study. We have prepared a short information sheet for them to read.

Your child will be asked to complete two questionnaire's, one of which is the shorter coping questionnaire. They will then be sent a link to complete the short coping questionnaire again in 2 weeks' time. This allows us to check if the coping questionnaire is working correctly.

Does my child have to take part?

No, it is up to your child to decide whether or not to take part. If they decide to take part they are free to withdraw (stop taking part in the study) at any time up to two weeks after filling in the questionnaires and without giving a reason. If you do take part in the study and you change your mind afterwards, you can just contact us and we will destroy all the information you gave us. Whether you decide to take part or not will not affect the standard of care that you or your child receives at the clinic.

What are the benefits of taking part?

'Coping' questionnaires for food allergy would help your child to let their clinician know in a quick and effective way how your child is managing and coping with their food allergy. This would help to direct health care and would also help clinicians see if there are any interventions that could support your child manage and cope with their food allergy more effectively. Your child can also enter a prize draw for [prize here] if they take part.

What are the disadvantages of taking part?

There are no disadvantages or risks to taking part. Your child can decide to stop filling in the questionnaires at any time.

What will I need to do if I decide to allow my child to take part?

If your child is happy to take part, please could you both complete the online consent forms on the online questionnaire, and allow your child to fill in the questionnaire. If your child does not want to fill in the questionnaires online you can contact Jenny Hammond by email on [redacted] and we can send you questionnaires and consent forms through the post.

INFORMATION ABOUT THE CONDUCT OF THE STUDY

Will the information I give in this study be kept confidential?

Yes, all information collected from you and your child for the study will be kept strictly confidential. That means that no one outside of the research team will see any of the information you give us. Each person taking part in the study will be given a code or study number that we will use when looking at what you said in your interviews. Information will be kept in a locked filing cabinet and on a password protected computer at Aston University for 7 years and then it will be destroyed. The procedures for handling, processing, storage and destruction of the questionnaire data collected during the study are compliant with the Data Protection Act 1998.

What will happen to the results of the study?

The information your child give us will be looked at by the study team and we will be able to make sure that the questionnaires we have developed are reliable and valid, that is they measure what we think they measure and will be useful for you as parents, for patients and for clinicians. We will write a report of the study which will be published and the results will be written up as part of a PhD. We can send you a summary of the results if you would like them. Your child's name will not be in anything we publish. The questionnaires will then be available for use by your child and your clinician.

What if there is a problem?

If you have any concerns or complaints about anything to do with this study, please speak to the research team and we will do our best to answer your questions. You can ring Dr Rebecca Knibb on [redacted] or email her on [redacted]
If she cannot help you and you still have any worries about the way in which the study has been conducted, then you should contact the Secretary of the University Research Ethics Committee, Mr John Walter, at [redacted] or telephone [redacted].

Who has reviewed the study?

This study has been looked by the Ethics Committee at Aston University and by the South West and Frenchay NHS research. These are a group of people who check research to make sure that it protects the safety, rights, wellbeing and dignity of anyone who takes part.

Can I get more information?

If your child is interested in taking part in this study but would like some more information before they decide whether to take part or not, please talk to Dr Rebecca Knibb or email us. Or please feel free to talk to your child's consultant at your clinic. If you would like to talk to an independent person about taking part in this study or about research in general in Psychology at Aston University please contact the Director of the Aston Research Centre for Children's and Young People's Health, Professor Helen Pattison, on [redacted]

If you would like independent advice on any aspect of this study, you can also contact the PALS (Patient Advice and Liaison Service) at the Sandwell and West Birmingham Hospital NHS Trust on 0121 507 5836.

Thank you for taking time to read this information sheet.

Yours sincerely

Jenny Hammond	Dr Rebecca Knibb
PhD Student	Chief Investigator

Research Team:

Jenny Hammond (PhD Student), Dr Knibb (chief investigator/supervisor), Dr Richard Cooke (co-investigator/supervisor)

Appendix 27: **Parent consent form (hardcopy)**

Ethics Approval Number_____

Participant ID number_____

Coping in children and adolescents with food allergy

STATEMENT OF INFORMED CONSENT FOR PARENTS OF CHILDREN AGED 8-16 YEARS

I agree for my child to participate in a research study to look at coping and develop a coping scale for children and adolescents with a food allergy. ☐

I and my child have read the study information (version 2) and know who to contact should we have any questions about participation in the study. ☐

I understand that my child's participation in the study is voluntary, and that they are free to withdraw at any time up to two weeks after taking part. We do not have to give any reasons or explanations for doing so. We have been provided with details ☐

I understand that relevant sections of my child's medical notes and data collected during the study may be looked at by individuals from Aston University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my child's records. ☐

I understand that all data my child provides will be kept confidential and stored securely on a password protected computer. Any hard copies of data will be stored in a locked filing cabinet. ☐

_____	_____	_____
Name of Child	Name of person giving consent for child	Relationship to child
	_____	_____
	Signature	Date
_____	_____	_____
Researcher	Signature	Date

Appendix 28: **Child consent form (hardcopy)**

Ethics Approval Number_____

Participant ID number_____

CONSENT FORM (CHILD)

Coping in children and adolescents with food allergy

Please initial each box

1. I have been told about this study and have had my questions answered ☐
2. I understand that I can stop at any time, without giving any reason and no one will mind. ☐
3. I understand that if I decide that I no longer want to take part in this study I can let the researcher know and they will remove my answers. ☐
4. I agree to take part in the above study. ☐

_____	_____	_____
Name of Child	Date	Signature
_____	_____	_____
Name of parent	Date	Signature
_____	_____	_____
Researcher	Date	Signature

Appendix 29: **Adolescent consent form (hardcopy)**

Ethics Approval Number_____

Participant ID number_____

Coping in children and adolescents with food allergy

STATEMENT OF INFORMED CONSENT (ADOLESCENTS)

Please initial each box to indicate you have read the statement:

I agree to participate in a research study looking at coping and developing a coping scale for children and adolescents with a food allergy. ☐

I have read the study information (version 2) and know who to contact should I have any questions about my participation in the study. ☐

I understand that my participation in the study is voluntary, and that I am free to withdraw at any time up to two weeks after taking part. I do not have to give any reasons or explanations for doing so. I have been provided with details of who I should contact if I wish to withdraw. ☐

I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from Aston University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

I understand that all data I provide will be kept confidential and stored securely on a password protected computer. Any hard copies of data will be stored in a locked filing cabinet. ☐

OPTIONAL I am happy to be contacted again about this research study. ☐

_____	_____	_____
Name of Participant	Signature	Date
_____	_____	_____
Researcher	Signature	Date

Appendix 30: **Child consent form (Qualtrics)**

Consent for children as written on the Qualtrics website:

	Yes (1)	No (2)
I have read the information sheet about this study and have had my questions answered. (1)	○	○
I understand that I can stop at any time, without giving any reason and no one will mind. (2)	○	○
I understand that if I decide that I no longer want to take part in this study I can let the researcher know and they will remove my answers. (3)	○	○
I agree to take part in the above study. (4)	○	○

Please enter a contact email address - we will send a link to complete this questionnaire again in 2 weeks' time. If you don't have an email address, you can use your parents.

_____

In the box below, please put the LAST 2 letters of your first name and the day of the month you were born. (E.g. NY19). This will be your unique participant code.

_____

Please sign below. If you are using a computer, you can use your mouse! If you are using a tablet, you can use your finger!

Please make a note of your participant code. If you wish to withdraw from the study, please email Jenny [redacted] with your participant code. You will need your parents or caregiver to complete the next consent form.

Appendix 31: **Adolescent consent form (Qualtrics)**

Consent for adolescents as written on the Qualtrics website:

	Yes (1)	No (2)
I have read the information sheet about this study and have had my questions answered. (1)	○	○
I understand that I can stop at any time, without giving any reason and no one will mind. (2)	○	○
I understand that if I decide that I no longer want to take part in this study I can let the researcher know and they will remove my answers. (3)	○	○
I agree to take part in the above study. (4)	○	○

Please enter a contact email address - we will send a link to complete this questionnaire again in 2 weeks' time. If you don't have an email address, you can use your parents.

_____

In the box below, please put the LAST 2 letters of your first name and the day of the month you were born. (E.g. NY19). This will be your unique participant code.

_____

Please sign below. If you are using a computer, you can use your mouse! If you are using a tablet, you can use your finger!

Please make a note of your participant code. If you wish to withdraw from the study, please email Jenny [redacted] with your participant code. You will need your parents or caregiver to complete the next consent form.

Appendix 32: **Parent consent form (Qualtrics)**

Consent for parents as written on the Qualtrics website:

	Yes (1)	No (2)
I agree for my child to participate in a research study to explore coping and develop a coping scale for children and adolescents with a food allergy (2)	○	○
I and my child have read the study information (version 2) and know how to contact should we have any questions about participation in the study. (3)	○	○
I understand that my child's participation in the study is voluntary and that they are free to withdraw at any time up to two weeks after taking part. We do not have to give any reasons or explanations for doing so. We have been provided with details of who to contact if we wish to withdraw. (4)	○	○
I understand that all my data my child provides will be kept confidential and stored securely on a password protected computer. Any hard copies of data will be stored in a locked filing cabinet. (7)	○	○

Please put in your child's unique participant code. (LAST 2 letters of your child's first name and the day of the month they were born).

_____

Please put in your unique participant code. (FIRST 2 letters of your first name and the day of the month you were born).

_____

Relationship to the child

_____

Please sign below - If you are using a computer, you can use your mouse! If you are using a tablet, you can use your finger!

Please make a note of your child's participant code. If they wish to withdraw from the study, please email [redacted] with their participant code.

Appendix 33: **Food allergy checklist (Qualtrics)**

Demographic and allergy checklist as written on the Qualtrics website:

How old are you?

_____

Are you:

- ○ Male (1)
- ○ Female (2)
- ○ Prefer not to say (3)

How many food allergies do you have?

_____

Do you have the following:

	Yes (1)	No (2)
Asthma (1)	☐	☐
Eczema (2)	☐	☐
Hay fever (3)	☐	☐

What are you allergic to? (Please tick as many as apply)

- ☐ Peanuts (1)
- ☐ Other nuts (2)
- ☐ Cow's milk (3)
- ☐ Egg (4)
- ☐ Soya (5)
- ☐ Fish (6)
- ☐ Shellfish (7)
- ☐ Latex (8)
- ☐ Tree pollen (9)
- ☐ Grass pollen (10)
- ☐ Other (11)

If you selected "other nuts", please write them down in the box below:

_____

If you selected "other", please write it down in the box below:

_____

Have you had any allergies to food which you can now eat? (Please tick as many as apply).

- ☐ Egg (1)
- ☐ Milk (2)
- ☐ Other (3)

If you selected "other", please say what allergies you have outgrown in the text box below:

_____

What medicine do you have for your food allergy? (tick as many as apply)

- ☐ Antihistamines (1)
- ☐ Adrenaline injection (Epi-Pen, Jext, Emerade) (2)
- ☐ None (3)

Which of the following symptoms do you get? (Tick as many as apply)

- ☐ Wheals/lumps on skin (2)
- ☐ Rash (3)
- ☐ Atopic dermatitis/eczema (4)
- ☐ Itchy skin (5)
- ☐ Dry skin (6)
- ☐ Scabby skin (7)
- ☐ Face swelling (8)
- ☐ Tingling/sore mouth (9)
- ☐ Swelling of lips of tongue (10)
- ☐ Vomiting (11)
- ☐ Bloated stomach (12)
- ☐ Stomach pain (13)
- ☐ Diarrhoea (14)
- ☐ Reflux/heartburn (15)
- ☐ Blocked up nose (16)
- ☐ Irritable or itchy nose (17)
- ☐ Runny nose (18)
- ☐ Throat tightening/difficulty swallowing (19)
- ☐ Breathing difficulties (20)

- ☐ Tight chest (21)
- ☐ Asthma (22)
- ☐ Wheeze/coughing (23)
- ☐ Blue around the lips (24)
- ☐ Collapse/faint (25)
- ☐ Other (26)

If you selected "other" please specify:

_____

Have you ever been to hospital with an allergic reaction to food?

- ○ Yes (1)
- ○ No (2)

Have you seen a doctor about your food allergy/allergies?

- ○ Yes (1)
- ○ No (2)

If you have seen a doctor, how were you tested for your food allergy? (tick as many as apply)

- ☐ Skin prick test (1)
- ☐ Blood test (2)
- ☐ Food challenge (3)
- ☐ Other (4)

If you selected "other", please specify:

_____

Appendix 36: **RCADS**

Appendix 37: **FAQLQ-CF and FAIM**

Appendix 38: **FAQLQ-TF and FAIM**

Appendix 39: **B-IPQ**

Appendix 40: Items from CS-FA with floor and ceiling effects

Items with floor effect	Items with ceiling effect
4. I only carry my medication with me if I'm going somewhere, I've not been before.	1. I carry my antihistamines with me in case I have an allergic reaction.
6. I avoid eating with other people, because I worry about having an allergic reaction.	2. I carry my adrenaline auto-injector (e.g. EpiPen, Jext) with me in case I have an allergic reaction.
12. I won't use my medication if other people are around me.	5. I check that there are no foods around me that I could be allergic to.
13. I eat food which may contain an allergen that I'm allergic to.	7. Before eating, I check the food labels to make sure the food is safe for me to eat.
22. When I'm at school, I am less careful about my food allergy.	9. When buying food at a shop, I try to look for something that is safe for me to eat.
38. I hide the fact I have a food allergy from other people, because I don't want them to know about it.	10. When going out for a meal, I ask what ingredients are in the food.
39. When I'm with my friends, I'm less careful about my food allergy, because I don't want to be different.	11. When I eat at school, I make sure that I'm not near any food that could give me an allergic reaction.
40. I eat the same foods as my friends, so I don't feel left out, even if I know I'm allergic to it.	14. If I'm offered food that I'm unsure about, I read the label or ask about the ingredients, to check if it's safe to eat.
41. I ignore my food allergy so I can do things with my friends that I normally wouldn't be able to do.	16. If I want to know more about my food allergy, I ask somebody (e.g. parents, teachers, friends) for more information.
43. When I'm at school, I don't eat with my friends in case I have an allergic reaction.	19. If I feel angry about my food allergy, I prefer to be by myself.
	20. I ask my Mum or Dad if my food is safe to eat.
	21. When going out for a meal, I prefer it if somebody else (e.g. Mum or Dad) checks what ingredients are in the food.
	42. I am more careful about my food allergy when I'm in a place that I'm not used to.

Appendix 41: **Final CS-FA**

Coping Scale for Food Allergy (CS-FA)

These questions are about how you cope with your food allergy. Please try to answer the questions on your own. You can ask your parents for help if you need to. There is no right or wrong answer!

For each of the questions below, circle the response that best describes how you feel about the statement.

1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Most of the time, 5 = Always

	Never	Rarely	Sometimes	Most of the time	Always
1. I carry my antihistamines with me in case I have an allergic reaction.	1	2	3	4	5
If you don't always carry your antihistamines with you, please explain why:					
2. I carry my adrenaline auto-injector (e.g. EpiPen, Jext) with me in case I have an allergic reaction.	1	2	3	4	5
If you don't always carry your adrenaline auto-injector with you, please explain why:					
3. I check that there are no foods around me that I could be allergic to.	1	2	3	4	5
4. I avoid eating with other people, because I worry about having an allergic reaction.	1	2	3	4	5
5. Before eating, I check the food labels to make sure the food is safe for me to eat.	1	2	3	4	5
6. I rely on my Mum or Dad to check food labels for me.	1	2	3	4	5
7. When going out for a meal, I ask what ingredients are in the food.	1	2	3	4	5
8. When I eat at school, I make sure that I'm not near any food that could give me an allergic reaction.	1	2	3	4	5
9. I won't use my medication if other people are around me.	1	2	3	4	5
10. If I'm offered food that I'm unsure about, I read the label or ask about the ingredients, to check if it's safe to eat.	1	2	3	4	5

1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Most of the time, 5 = Always

11. If I want to know more about my food allergy, I ask somebody (e.g. parents, teachers, friends) for more information.	1	2	3	4	5
12. I rely on my Mum or Dad to carry my medication for me.	1	2	3	4	5
13. If I feel upset about my food allergy, I prefer to be by myself.	1	2	3	4	5
14. I ask my Mum or Dad if my food is safe to eat.	1	2	3	4	5
15. When going out for a meal, I prefer it if somebody else (e.g. Mum or Dad) checks what ingredients are in the food.	1	2	3	4	5
16. I avoid talking to my friends about my food allergy.	1	2	3	4	5
17. If I need to use my adrenaline auto-injector (e.g. EpiPen, JEXT), I prefer someone else to do it for me.	1	2	3	4	5
18. I avoid social events (e.g. birthday parties or school trips), because of my food allergy.	1	2	3	4	5
19. If I feel upset about my food allergy, I talk to someone close to me about it.	1	2	3	4	5
20. I think to myself, "things could be worse," to feel better about my food allergy.	1	2	3	4	5
21. I compare myself to others, to feel better about my food allergy.	1	2	3	4	5
22. If I'm feeling upset about my food allergy, I distract myself by doing things that I like.	1	2	3	4	5
23. I look for the positives about my food allergy to help me feel better.	1	2	3	4	5
24. If I feel worried about my food allergy, I speak to somebody (e.g. parents, teachers, friends) about it.	1	2	3	4	5

1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Most of the time, 5 = Always

25. I hide the fact I have a food allergy from other people, because I don't want them to know about it.	1	2	3	4	5
26. When I'm with my friends, I'm less careful about my food allergy, because I don't want to be different.	1	2	3	4	5
27. I eat the same foods as my friends so I don't feel left out, even if I know I'm allergic to it.	1	2	3	4	5
28. I ignore my food allergy so I can do things with my friends that I normally wouldn't be able to do.	1	2	3	4	5
29. I am more careful about my food allergy when I'm in a place that I'm not used to.	1	2	3	4	5
The following questions are about going out <u>without</u> any adults. If you always go out with an adult, please go to the final question.					
30. When I go out with my friends, I take my medication with me to stay safe.	1	2	3	4	5
31. When I go out for a meal with my friends, I tell staff about my food allergy.	1	2	3	4	5
32. When I go out for a meal with my friends, I avoid foods that could give me an allergic reaction.	1	2	3	4	5
33. When I go out for a meal with my friends, I tell my friends if I cannot eat the food there.	1	2	3	4	5
34. When I go out with my friends, I am less careful about my food allergy.	1	2	3	4	5
35. If my friends are going out for a meal, I won't go with them.	1	2	3	4	5
Is there anything else that you do to cope with your food allergy? If so, please write it below:					

Instructions:

Children/adolescents should circle the response that best fits how they feel about that statement. The responses are on a 5 point Likert scale and reflect how often they use that particular coping strategy. There are 29 core items that should be completed by children/adolescents, and 6 optional items. Optional items should only be completed by children/adolescents who socialise without an adult.

There are 4 subscales to this scale:

Self-management
Items: 6, 11, 12, 14, 15, 17, 19, 24

Social Support
Items: 1, 2, 3, 4, 5, 7, 8, 10, 18, 29

Avoidance and Minimisation
Items: 9, 13, 16, 25, 16, 27, 28

Positive Beliefs
Items: 20, 21, 22, 23

The score for each sub-scale is computed by adding up the numbers circled for each question in the sub-scale and dividing by the number of items in that sub-scale, to get a mean score ranging from 1-5. There are no reversed items. A higher score represents greater use of that particular coping strategy. There is no overall score, or composite scores for this scale. It is best used as a way of identifying what types of coping strategies are used and how frequently.

Information about this scale

Reliability analysis conducted on the scale has demonstrated good alpha values above 0.7, indicating that the CS-FA is a reliable measure

Total Scale	.773
Sub-Scales	
Social support	.841
Self-management	.784
Risk and minimisation	.744
Positive beliefs	.756

A test re-test analysis also demonstrated 'good' (0.75>x>0.9) to 'excellent' (x>0.9) ICC scores across all subscales, indicating that the CS-FA is a stable measure.

	ICC	**95% CI**		**F**	**Sig**
		Higher	Lower		
CS-FA Sub-Scales					
Social support	.894	.966	.671	8.997	.000
Self-management	.914	.972	.729	10.888	.000
Disengagement and minimisation	.873	.959	.620	8.108	.000
Positive beliefs	.619	.874	-.102	2.718	.041

This scale has been tested and validated on children and adolescents aged 8-16 years old with a clinical diagnosis of food allergy. It was developed using the control-based model of coping (Compas et al. 2001) which is a three-factor model of coping.

Primary- control coping - efforts to change a stressor (such as problem-solving) or change the emotional reaction to a stress (such as emotional expression).

Secondary-control coping - which uses efforts to adapt to stress, such as using reappraisal, positive thinking, acceptance and distraction.

Disengagement coping - which uses efforts to steer away from the stressor, or one's reaction to the stressor, such as avoidance or denial.

'Self-management' and 'Social Support' falls under *Primary-Control Coping*, 'Positive Beliefs' falls under *Secondary-Control Coping* and 'Disengagement and Minimisation' falls under *Disengagement Coping.*

If this scale is being used as part of research, please cite the authors:

Hammond, J., Cooke, R, Knibb R.C (2018). Development and preliminary validation of the Coping Scale for Food Allergy (CS-FA) for children and adolescents. *Manuscript in preparation.*

References:

Compas BE, Connor-Smith JK, Saltzman H, Thomsen AH, Wadsworth M. Coping with stress during childhood and adolescence: Progress, problems, and potential. Psychological Bulletin. 2001;127:87–127.